Living in two worlds: Intentional personal development of autistic individuals

by

Ljiljana Vuletic

A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy

Graduate Department of Human Development and Applied Psychology
Ontario Institute for Studies in Education
University of Toronto

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Abstract

Despite an increased interest in autism over the last decades, little research exists about life outcomes of autistic adults. The earliest follow-up studies of autistic individuals suggested that self-understanding and conscious efforts to change could be crucial factors in successfully reaching good life outcomes. However, these initial suggestions have not been further investigated. Therefore, this exploratory qualitative study examined the lives of eight high-functioning autistic adults aged 25 to 63, from their own perspectives, through in-depth, semi-structured interviews, to consider the relation of self-understanding and conscious efforts to change—in this study referred to as intentional personal development—to their life outcomes. All participants demonstrated a level of self-understanding beyond what would be predicted by current theoretical models of autism. Their self-understanding was assessed through participants’ self-definitions, meaning-making of life experiences, and understanding of emotions. In their self-definitions, the participants emphasized their abilities and personality characteristics, rather than their disabilities. For their self-defining memories, as indicators of their meaning making of life experiences, most participants chose positive experiences related to their personal development. Their autobiographical accounts revealed that most participants possess a large
repertoire of emotion words, supporting an understanding of emotions. When a good life outcome is defined traditionally—as being employed, living independently, and having social relationships—this study, contrary to expectations, did not provide overwhelming evidence for the significant role of intentional personal development in achieving this. However, when a good life outcome is defined in terms of achieving personal excellence, then the study did provide confirmation of intentionality as important to attaining good life outcomes. This study therefore suggests that traditional life outcome measures are inadequate for assessing the life outcomes of autistic individuals because such measures do not take into account the individuals’ own sense of satisfaction with themselves and with their lives.
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Chapter 1 Introduction

Research on autism—a human condition characterized by serious difficulties with understanding and adjusting to the social world—has so far focused on two classes of influences on the development of autistic individuals: biological and social. However, people are also agents in their own lives—they have dreams and visions about their future and work towards realizing them. This agentic (or proactive) aspect of the development of autistic individuals and its consequences for their social adaptation has never been empirically explored.

Autism is currently defined as a spectrum of developmental disorders characterized by impairments in social interaction and communication and by the presence of repetitive and stereotyped patterns of interests and activities (American Psychiatric Association [APA], 1994, 2000). It occurs in 1% of the population (Baird et al., 2007), with a male to female ratio of 4:1 (Fombonne, 2005). Evidence for the occurrence of what we now call autism transcends time (Frith, 2003; Houston & Frith, 2000), culture (Connors & Donnellan, 1998; Grinker, 2007; Lotter, 1978) and socio-economic status (Fombonne, 2005).

The causes of autism are still unknown; however, there is strong evidence from twin, family, and adoption studies (Bailey et al., 1995; Folstein & Rutter, 1977; Le Couteur et al., 1996) that it is highly heritable (for a recent review, see, Curran & Bolton, 2009). There is also no curative treatment for autism (Volkmar, Lord, Bailey, Schultz, & Klin, 2004), and although a variety of behavioral and psycho-educational intervention programs exist, their long-term effectiveness is not yet known (Howlin, 2004; Ospina et al., 2008; S. J. Rogers & Vismara, 2008). However, current evidence suggests that existing interventions do not significantly affect the long-term outcomes for autistic individuals (Bodfish, 2004; Howlin, 2002). Contrary to the original estimates of high co-occurrence of autism with intellectual disability (i.e., mental retardation), more recent data suggest that this co-occurrence may be true for only about 25–30% of autistic individuals (Chakrabarti & Fombonne, 2001; 2005). Autism without intellectual disability is often referred to as high-functioning autism or Asperger syndrome (Attwood, 1998, 2006; Frith, 2004; Schopler, 1998); while the use of these terms is disputed—as will be discussed below—it is this type of autism that is explored in this study.
Research indicates that only 12% of autistic individuals without intellectual disabilities, who are, at least theoretically, capable of achieving “good life outcomes”—typically defined as living independently, having a job, and having social relationships—succeed in this respect (Engström, Ekström, & Emilsson, 2003; Howlin, Goode, Hutton, & Rutter, 2004). Unfortunately, there is little information available about the factors that contribute to good life outcomes for autistic individuals (Howlin et al., 2004). Kanner, who originally described autism as a clinical condition (1943), suggested that the main contributing factors in determining life successes for autistic individuals might be enhanced self-awareness (that includes the awareness of one’s differentness) and a constructive reaction to that awareness (Kanner, Rodriguez, & Ashenden, 1972). Despite the practical importance of knowing the factors that contribute to good life outcomes for autistic individuals, this suggestion has never been explored further.

The main aim of this study is to take the suggestion of Kanner and his colleagues seriously and to explore the importance of self-awareness and intentional development of autistic individuals for the way they live their lives. To this end, I use a phenomenological approach, to conduct a detailed study of autistic adults, in which I explore their life experiences and the meaning they make of them.

1 What is Autism?

There are many ways to describe autism. Standpoints from which one can look at autism include professional (e.g., psychiatric, psychological, neuroscientific, genetic, pharmacological, educational, sociological, philosophical, anthropological, historical, and judicial), experiential (e.g., parental, grandparental, spousal, siblings’, friends’, coworkers’, classmates’, and personal reports), and cultural (e.g., literary, media, and lay or public opinion). In this section, I consider four perspectives—the most relevant to this project—in detail: two professional (psychiatric and psychological) and two experiential ( parental and personal).1 (The cultural perspective is not

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1 Of course, in many cases these perspectives are not as clear-cut as one might imagine. For example, the differences between psychiatric, psychological, and neuroscientific perspectives are more blurred today than they were in the
considered independently here because it is of more interest to sociologists and literary, film, and other media researchers; a recent overview of this perspective could be found in Osteen, 2008.) Because all of the perspectives provide important insights, findings from all of them are interspersed throughout this thesis. However, I begin with the psychiatric perspective because historically autism was first described from this perspective.

1.1 Psychiatric Perspective

1.1.1 Historical Background

As a clinical condition, autism was first formally described by Leo Kanner, an Austrian-American psychiatrist, in his 1943 paper entitled “Autistic disturbance of affective contact.” Although historically, the term “autism,” from the Greek “autos” (meaning self), was coined by Swiss psychiatrist Eugen Bleuler (1910/1911/1912) to refer to social withdrawal and self-centered thinking in schizophrenia, Kanner used it to refer to a previously unknown, or rather, unlabeled, condition. While children resembling those described by Kanner had been described in scientific literature before (e.g., Itard, 1801/1807/1972 and M. Klein, 1930; for reviews, see Frith, 2003; Wolff, 2004), they were never labeled as belonging to a specific clinical condition. Based on the case histories of eleven 2- to 8-year-old children, whom he referred to as “autistic,” Kanner identified several clinical features of a “unique ‘syndrome,’ not heretofore reported” (p. 242). These features included an inability to relate to people and to develop relationships, abnormal speech pattern (including a delay in language development, an inability to use
language for communication, delayed echolalia, and pronoun reversal), monotonous and repetitive behavior, an obsessive desire for the maintenance of sameness, an excellent rote and event memory, and good intelligence. Kanner further suggested that all these features could be explained by two needs—for “aloneness and sameness” (p. 249). Accordingly, he (Eisenberg & Kanner, 1956) later isolated “extreme autistic aloneness” and “insistence on sameness” as the core features of early infantile autism, as he termed the new clinical condition (Kanner, 1944).

He described “extreme autistic aloneness” as follows:

There is from the start an extreme autistic aloneness [italics in original] that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside. Direct physical contact or such motion or noise as threatens to disrupt the aloneness is either treated “as if it weren’t there” or, if this is no longer sufficient, resented painfully as distressing interference. (1943, p. 242)

With regard to the “insistence on sameness,” Kanner (1943) made the following observation:

There is a marked limitation in the variety of his spontaneous activities. The child’s behavior is governed by an anxiously obsessive desire for the maintenance of sameness [italics in original] that nobody but the child himself may disrupt on rare occasions. Changes of routine, of furniture arrangement, of a pattern, of the order in which everyday acts are carried out, can drive him to despair . . . .

This insistence on sameness led several of the children to become greatly disturbed upon the sight of anything broken or incomplete. A great part of the day was spent in demanding not only the sameness of the wording of a request but also the sameness of the sequence of events. (p. 245)

Kanner (1943) also observed that autistic aloneness was present from birth, which he believed differentiates it from all previously described clinical conditions, including schizophrenia, with which, he suggested, it might have been confused in the past. Because autistic aloneness was present from the beginning of life, Kanner concluded that it was caused by an innate social and emotional deficit. As he put it, “We must, then, assume that these children have come into the world with innate inability to form the usual, biologically provided affective contact with people” (p. 250).
A year later,² Hans Asperger (1944/1991), a Viennese doctor, unaware of Kanner’s paper, used the terms *autistic psychopathy*, *autistic personality* and *autism* to encompass a similar pattern of behaviors in a group of more than 200 older children and adolescents he observed in his hospital over a period of 10 years. In his paper, Asperger presented detailed accounts of four of the children along with his analysis of the similarities and differences he observed among the larger group of children. He concluded that “the essential feature of the condition is a disturbance of adaptation to the social environment” (p. 87). His descriptions of two of the children’s behavior illustrate this point. First is of eight-and-a-half-year old Harro L.:

Through the length of his stay on the ward he remained a stranger. One would never see him join in a game with others. Most of the time, he sat in a corner buried in a book, oblivious to the noise or movement around him. (p. 56)

Second is of seven-and-a-half-year old Ernst K.:

To the very end of his stay on the ward he remained a stranger, walking between the other children without ever properly taking part in their games. At most, he would tell off one or other of them, or suddenly start a furious fight, either for no apparent reason or because somebody had teased him. (p. 61)

Asperger also identified a number of other “typical and unmistakable characteristics of autistic psychopathy” (p. 64). They include abnormalities in many psychological domains—most are negative (as it is typical of clinical conditions); however, there are several positive ones.

*Negative aspects of autism.* Asperger identified the negative characteristics of autism in the following areas: (a) non-verbal communication, (b) language, (c) interests, (d) attention, (e) emotions, (f) movement, (g) sensory processing, and (h) conduct.

(a) Some of the autistic features of *non-verbal communication* include a lack of eye contact and of facial, gestural, and vocal expressiveness. Asperger’s description of autistic children’s eye gaze is particularly incisive:

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² In fact, Asperger used the term “autistic psychopathy” in his doctoral thesis, which he completed and submitted in 1943, the same year Kanner published his paper (Frith, 1991, p. 6).
With our children here, there is a fundamental difference. Hardly ever does their glance fix brightly on a particular object or person as a sign of lively attention and contact. . . . The disturbance is particularly clear when they are in conversation with others. Glance does not meet glance as it does when unity of conversational contact is established. (pp. 68–9)

When describing the vocal characteristics of autistic children, Asperger stressed not only a lack of a voice expressiveness but also its peculiarities, such as a lack of speech modulation, the “normal speech melody, [and] the natural flow of speech” (p. 42). He wrote,

Sometimes the voice is soft and far away, sometimes it sounds refined and nasal, but sometimes it is too shrill and ear-splitting. In yet other cases, the voice drones on in a sing-song and does not even go down at the end of a sentence. Sometimes speech is over-modulated and sounds like exaggerated verse-speaking. (p. 70)

(b) Asperger also identified several characteristic features of “autistic language” (p. 70). For example, he noted that it is adult-like and that even as toddlers, autistic children talk like grown-ups. He particularly stressed the unnatural and noncommunicative feel of “autistic language”:

They all have one thing in common: the language feels unnatural, often like a caricature, which provokes ridicule in the naive listener. One other thing: autistic language is not directed to the addressee but is often spoken as if into empty space. This is exactly the same as with autistic eye gaze which, instead of homing in on the gaze of the partner, glides by him. (p. 70)

(c) According to Asperger, another prominent autistic feature is the preoccupation with special interests, which are often “very narrow, circumscribed and isolated” (p. 72). Asperger noted that autistic interests are “usually far beyond the interests of other children of the same age” (p. 71), often “remote from reality” (p. 72), and developed to “an excessive extent” (p. 82). Examples of such interests include spaceships, chemistry, number calculations, calendars, poisons, “the tram lines of Vienna with their terminals” (p. 75), and collecting objects (sometimes until a pre-specified number of objects is collected, such as 1000 matchboxes).

(d) When characterizing the attention of autistic children, Asperger noted that in contrast to children with neurological disorders, who are easily distracted by external stimuli, autistic children seem to be distracted by internal stimuli. Moreover, they are, he wrote,
from the start, not interested in directing their attention to outside stimuli, in this case, what the school wants them to attend to. They follow their own ideas, which are mostly far removed from ordinary concerns, and do not like to be distracted from their thoughts. (p. 76)

Asperger believed that this kind of inattention was the reason why most autistic children he observed had learning difficulties. He also noted that autistic children’s problems with attention could make the results of psychological testing unreliable. For example, he wrote the following observation about the testing of one of the children, Harro L.:

Very often, he shut off completely when a question did not interest him. Sometimes he did not seem to hear the question. A lot of energy went into simply making him do the tasks. Again and again he went off on a tangent and had to be brought back. However, once his attention was engaged, his performance could be remarkably good. (p. 53)

(e) In the area of emotionality, Asperger observed a “poverty of emotions” as well as “qualitative difference, a disharmony in emotion and disposition” (p. 83). He wrote,

As soon as one starts to work with these children, one is struck by a distinctive emotional defect which one may well consider an ultimate cause of their social disturbance. This defect is apparent in their isolation while they are in the midst of other people and in their contrariness with their environment and especially their closest family. (p. 80)

However, Asperger believed that autistic children are “capable of strong feelings” (p. 83). He illustrated this claim with cases of autistic children’s severe homesickness after hospitalization.

(f) In the area of movement, Asperger noticed movement stereotypes and motor clumsiness. Movement stereotypes ranged from simple rhythmic rocking to monotonous play activities such as lining up toys according to color, size, or some other visible or invisible characteristics (as opposed to playing with them). With regards to their clumsiness, he described their difficulties with self-care and other everyday activities, as well as with catching a ball, handwriting, and participating at the work-table or in physical education classes. He also often made remarks about autistic children’s odd posture and gait. When describing one of the children, Fritz V., he wrote, “He never ‘swung’ in any rhythm. He had no mastery over his body” (p. 44).
(g) Autistic children’s sensory processing also caught Asperger’s attention. He observed that autistic children were often hyper- or hypo-sensitive to a variety of everyday sensory stimuli. For example, they strongly disliked velvet, silk, and chalk, and were both hyper- and hypo-sensitive to different kinds of noise.

(h) In the area of conduct, Asperger noted autistic children’s uninhibited and impulsive behavior, aggressiveness, argumentativeness, non-compliance, negativism, and “naughtiness” (p. 47). He also observed that a lot of the aggressiveness of autistic children seemed to be provoked by bullying, to which they were regularly subjected to because of their differentness from others.

Positive aspects of autism. Asperger emphasized that there were also “positive aspects of autism” (p. 50) and that his mission was to describe and understand autistic children’s “difficulties and deficits as well as their special achievements” (p. 39). In fact, it appears that this constellation of coexisting strengths and weaknesses made autism a particularly interesting phenomenon for Asperger. He was particularly impressed with the “autistic originality” (p. 55) of language, thought, and interests. For example, he wrote, “Autistic children have the ability to see things and events around them from a new point of view” (p. 71). He also believed that autistic children are “good at logical thinking, and the ability to abstract is particularly good” (p. 49). He also described the exceptional rote memory and good number skills of some autistic children.

Moreover, Asperger believed that some of the negative aspects of autism, such as narrow special interests and single-mindedness, could, under favorable circumstances, be advantageous for some autistic individuals. He claimed that, at least in the case of autistic individuals with intact intelligence, their social difficulties could be compensated by their abilities and personality characteristics and that such individuals can achieve “exceptional achievements in later life” (p. 37). He wrote,

Able autistic individuals can rise to eminent positions and perform with such outstanding success that one may even conclude that only such people are capable of certain achievements. It is as if they had compensatory abilities to counter-balance their deficiencies. Their unswerving determination and penetrating intellectual powers, part of their spontaneous and original mental activity, their narrowness and single-mindedness,
as manifested in their special interests, can be immensely valuable and can lead to outstanding achievements in their chosen areas. (p. 88)

Asperger (1979) even suggested that a little bit of autism may be an essential ingredient for success in fields such as art and science:

It seems that for success in science or art a dash of autism is essential. For success the necessary ingredient may be an ability to turn away from the everyday world, from the simply practical, an ability to re-think a subject with originality so as to create in new, untrodden ways, with all abilities canalised into the one speciality. (p. 49)

“Unfortunately,” Asperger (1944/1991) wrote, “in the majority of cases the positive aspects of autism do not outweigh the negative ones” (p. 74). It seems that Asperger based this conclusion on his observation that autism can happen at any level of intelligence. He wrote,

Autism occurs at different levels of ability. The range encompasses all levels of ability from the highly original genius, through the weird eccentric who lives in a world of his own and achieves very little, down to the most severe contact-disturbed, automaton-like mentally retarded individual. (p. 74)

Asperger (1944/1991) further noted that because of autistic children’s communicative idiosyncrasies, it is often difficult to decide whether they are “particularly able or mentally retarded” (p. 64).

**Other observations.** Asperger (1944/1991) made several other important observations and conclusions about autism. For example, he noted several developmental aspects of autism. He wrote that autistic features could be noticed as early as the second year of life and that, although expressions of autism change with development, its essential aspects remain throughout life:

A crucial point which makes clear that the autistic personality type is a natural entity is its persistence over time [italics in original]. From the second year of life we find already the characteristic features which remain unmistakable and constant throughout the whole life-span. Naturally, intelligence and personality develop and, in the course of development, certain features predominate or recede so that the problems presented change considerably. Nevertheless, the essential aspects of the problem remain unchanged. In early childhood there are the difficulties in learning simple practical skills and in social adaptation. These difficulties arise out of the same disturbance which at school age cause learning and conduct problems, in adolescence job and performance problems, and in adulthood social and marital conflicts. (pp. 67–8)
Asperger (1944/1991) also noted that autistic children were “almost exclusively” boys (p. 84) and that autistic features could be found in family histories of autistic children, which suggested that autism was a genetic condition. Asperger also believed that autism is a “type of personality disorder” (p. 39), unrelated to schizophrenia or psychosis. Consequently, he used the terms autism, autistic psychopathy, and autistic personality interchangeably. It is important to note the difference in use of the term “psychopathy” in Asperger’s and our time. Today, the term “psychopathy” is used to refer to antisocial behavior (APA, 1994). However, at the time of Asperger’s writing, in German psychiatry, where the term originates, the term “psychopathy” was a generic term denoting a heterogeneous group of abnormal personalities, which was conceptualized on the continuum with normal personality (R. Blackburn, 1998). Moreover, research has shown that autistic and psychopathic traits (in the current sense) are unrelated (J. Rogers, Viding, Blair, Frith, & Happé, 2006).

Another important observation Asperger (1944/1991) made concerns the individual differences that exist among autistic individuals. He noted that autistic individuals differ not only by the degree of autism and ability but also by their interests and personalities:

The autistic personality is highly distinctive despite wide individual differences. Our method would have failed if it ignored the differences and if it let each child’s unique personality vanish behind the type. Autistic individuals are distinguished from each other not only by the degree of contact disturbance and the degree of intellectual ability, but also by their personality and their special interests, which are often outstandingly varied and original. (p. 67)

Although children described by Kanner and Asperger had similar problems with social and emotional relationships and in stereotypical behavior, they differed in several respects. For example, unlike children described by Kanner, Asperger’s children were all boys, their speech was not always delayed (although it was always idiosyncratic), their intelligence seemed to be higher (although Asperger noted that it could be lower, he did not describe such cases), and they had greater motor difficulties.

While Kanner’s account of autism generated a lot of interest and many clinical and empirical accounts of autism were published soon thereafter (for a review, see Rimland, 1964), Asperger’s
paper did not receive much attention. Asperger wrote in German, during World War II, and his work was unknown to the English-speaking world until the 1970s when Bosch (1962/1970) and van Krevelen (1971) compared Asperger’s and Kanner’s descriptions of autism. However, wider recognition of Asperger’s type of autism came only 10 years later with Lorna Wing’s (1981) influential review of both Asperger’s and her own cases.

Although Kanner’s and Asperger’s descriptions caught the most attention and are usually considered “the first” accounts, Wolff (1996) discovered that the Russian neurologist Ewa Ssucharewa, writing in German in 1926, described a group of six children with very similar characteristics to those described by Asperger. Although Ssucharewa used the term “schizoid personality disorder of childhood” to classify the children, she also used the term “autistic” when describing some of the children’s characteristics, such as an “autistic, inner directed attitude” (p. 126) and a “tendency to autistic reactions” (p. 132). In her summary, under the subtitle “An autistic attitude,” she wrote, “All affected children keep themselves apart from their peers, find it hard to adapt to and are never fully themselves among other children” (p. 129).

However, despite a lot of interest in autism—perhaps best reflected in the appearance of a new journal, the *Journal of Autism and Childhood Schizophrenia* in 1971—autistic children continued to be diagnosed as schizophrenic until 1980 (Grinker, 2007; Rutter, 1972). It is only with the publication of the third edition of the standard nomenclature of mental disorders, *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III; APA, 1980), that autism became a diagnostic entity on its own. At that time, only Kanner’s type of autism was recognized—termed Infantile Autism and included as one of a group of Pervasive Developmental Disorders (PDD). According to the DSM-III, autism was a disorder involving a lack of responsiveness to others, severe impairments in communication and language, and bizarre responses to the environment.

### 1.1.2 Contemporary Views: DSM-IV

Today, the two clinical conditions described by Kanner and Asperger are part of a larger diagnostic group of *Pervasive Developmental Disorders* (PDD) characterized by impairments in social interaction and communication, and by restricted and repetitive interests and activities.
(APA, 1994, 2000). According to the *DSM-IV* (APA, 1994), Kanner’s and Asperger’s types of autism are now called *Autistic Disorder* and *Asperger’s Disorder*, respectively. Other disorders included under the PDD category are *Childhood Disintegrative Disorder*, *Rett’s Disorder*, and *Pervasive Developmental Disorder Not Otherwise Specified* (PDD-NOS). Informally, *Pervasive Developmental Disorders* are also referred to as autism spectrum disorders (ASD) or autism (Filipek et al., 1999; Lord & Risi, 1998; Wing, 1996). In this thesis, I use the term “autism” to mean “autism spectrum disorders,” and I will focus my attention on *Autistic Disorder* (without mental retardation; to be explained) and *Asperger’s Disorder*. (Other terms for subtypes of autism spectrum disorders include: classical or Kanner’s autism, for *Autistic Disorder*; Asperger syndrome and high-functioning autism, for *Asperger’s Disorder*; and atypical autism for *Pervasive Developmental Disorder Not Otherwise Specified*.)

The *DSM-IV* diagnostic criteria are designed specifically for children and include the following impairments: In the *social domain*, a qualitative impairment in the use of non-verbal communication to regulate social interaction (e.g., eye gaze, facial expression, body postures, and gestures), lack of interest in sharing one’s pleasure with others, lack of age appropriate peer relationships, and lack of social-emotional reciprocity (two impairments from this group are needed for a diagnosis of either *Autistic Disorder* or *Asperger’s Disorder*). In the *communication domain*, delayed or absent spoken language, lack of conversational reciprocity, stereotyped, repetitive, or idiosyncratic language, and a lack of developmentally appropriate imitation and pretend play (at least one impairment from this group is necessary for a diagnosis of *Autistic Disorder* whereas there should be no clinically significant delay in language for a diagnosis of *Asperger’s Disorder*). In the *behavior domain*, all absorbing preoccupation with stereotyped and restricted interests, insistence on routines and rituals, and stereotyped and repetitive movements (e.g., rocking and hand flapping), and preoccupations with parts of objects (at least one impairment from this group is necessary for a diagnosis of either *Autistic Disorder* or *Asperger’s Disorder* (APA, 1994).

The manual also specifies that in order to be diagnosed with *Autistic Disorder*, a child must meet at least six criteria across the three domains and that the onset of delays or abnormal functioning must be before the age of three. In the case of *Asperger’s Disorder*, the manual further specifies that there should be no delay in cognitive development, but that there must be clinically
significant impairment in social, occupational, or some other important area of functioning (APA, 1994).

If a child has less, or milder, autistic features than required for *Autistic or Asperger’s Disorder* (or other PDD conditions), he or she could be given a diagnosis of PDD-NOS. The final two PDD disorders, *Childhood Disintegrative Disorder* and *Rett’s Disorder* are rare disorders characterized by serious deterioration and are considered atypical for autism (Volkmar, State, & Klin, 2009). According to the *DSM-IV*, they are diagnosed only when development has been normal until the age of two, in case of the former, and 5 months, in case of the latter, after which time a marked regression occurred (APA, 1994, 2000).

The *DSM-IV* view of autism spectrum disorders has been widely criticized for a variety of reasons, including its treatment of these disorders as being qualitatively different from one another. Even before the publication of the *DSM-IV*, Wing (1988, 1991) argued that Kanner’s and Asperger’s types of autism are on the same “seamless continuum” (or autistic spectrum; 1991, p. 103) and that they differ only in degrees of impairments. She found support for her argument in cases “where the same individual was typically autistic in his early years but made progress and as a teenager showed all characteristics of Asperger’s syndrome” (p. 103). Many other clinicians and researchers expressed similar ideas (e.g., Attwood, 1998, 2006; Gillberg, 1991; Szatmari, 2000). Attwood (1998) further suggested that the diagnosis of *Autistic Disorder* should be “regularly reviewed to examine whether Asperger’s Syndrome is now a more accurate diagnosis” (pp. 23–4). However, others, most notably Volkmar and his colleagues (e.g., Klin & Volkmar, 1997; Klin, Volkmar, Sparrow, Cicchetti, & Rourke, 1995; Volkmar, State, & Klin, 2009) argued that *Asperger’s Disorder* and high-functioning autism are not the same.³ According to Klin and Volkmar (1997), they are different in that the time of the onset of *Asperger’s Disorder* is later, the outcome is better, social and communication impairments are milder, circumscribed interests are more prominent, motor clumsiness is more frequent, and similar difficulties exist in family history. Nevertheless, available empirical evidence does not support this claim (e.g., Cuccaro et al., 2007; Howlin, 2003; Manjiviona & Prior, 1999; Ozonoff, 2004; Waterhouse, 2007).

³ It should be noted that Volkmar was involved with the development of the *DSM-IV* and *DSM-IV-TR* criteria for autism (APA, 1994, 2000).
South, & Miller, 2000; South, Ozonoff, & McMahon, 2005; for a recent review see, Witwer & Lecavalier, 2008). Consequently, most clinicians and researchers do not share the DSM-IV view on the two major “types” of autism and believe that Asperger’s autism is just a milder form of Kanner’s autism (e.g., Attwood, 1998, 2006; Eisenmajer et al., 1996; Frith, 1991, 2004; Gillberg, 1985, 1989; Gillberg, Gillberg, Rastam, & Wentz, 2001; Howlin, 2000a, 2000c; Manjiviona & Prior, 1995; J. N. Miller & Ozonoff, 2000; Schopler, 1985, 1996, 1998; Wing, 1991, 1998). This view is best reflected in the common use of terms such as high-functioning autism, autism without mental retardation, and Asperger’s Disorder interchangeably, which is the approach I follow in this thesis.

The DSM-IV diagnostic criteria themselves have also been criticized (e.g., Eisenmajer et al., 1996; Howlin, 2000a, 2003; S. D. Mayes, Calhoun, & Crites, 2001; J. N. Miller & Ozonoff, 1997). As reviewed above, according to the DSM-IV (APA, 1994), the main difference between Autistic and Asperger’s Disorders is in the absence of cognitive and language delay. However, many clinicians and researchers believe that the presence of language delay does not preclude a diagnosis of Asperger’s Disorder (e.g., Eisenmajer et al.; Gillberg, 1989, 1991, 2002; Howlin, 2000a, 2003; J. N. Miller & Ozonoff, 1997; Tantam, 1991; Wing, 1981). In fact, a recent review of Asperger cases found that two out of four had a language delay (J. N. Miller & Ozonoff, 1997).

Similarly, according to the DSM-IV criteria for Asperger’s Disorder, the diagnosis of Asperger’s Disorder is not given if the criteria for Autistic Disorder are also met (a so-called precedence rule). Interestingly, all four cases described by Asperger met current criteria for Autistic Disorder. In other words, none of the children Asperger described would be diagnosed with Asperger’s Disorder today (J. N. Miller & Ozonoff, 1997). This has led some to suggest that the DSM-IV criteria for Asperger’s Disorder may not apply to anybody (Eisenmajer et al., 1996; S.

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4 It is also important to note that these clinicians did not use the DSM-IV criteria; rather, they used the criteria they developed based on Asperger’s original descriptions. Several such criteria exist (e.g., Gillberg & Gillberg, 1989; Szatmari, Brenner, & Nagy, 1989; Tantam, 1988; Wing, 1981). According to a recent study (S. D. Mayes et al., 2001), many clinicians prefer some of the alternative criteria to the DSM-IV criteria. Importantly, in a study that compared six different diagnostic criteria for Asperger syndrome (Ghaziuddin, Tsai, & Ghaziuddin, 1992) only about half of the autistic individuals would be diagnosed with Asperger syndrome regardless of the criteria (i.e., approximately half of the sample met only some but not all sets of criteria).
D. Mayes et al., 2001; Szatmari, Archer, Fisman, Streiner, & Wilson, 1995)! Moreover, Szatmari (Szatmari, 2000) argued that if the criteria for *Autistic Disorder* are met in the absence of cognitive and language delay, then a diagnosis of *Asperger's Disorder* should be given (not of *Autistic Disorder* as required by the *DSM-IV* criteria).

The *DSM-IV* category of *PDD-NOS* generated even more confusion than *Asperger's disorder* (Volkmar et al., 2009). This category was introduced to cover cases with “fewer or less severe symptoms” (Towbin, 2005, p. 166); however, due to an error in the *DSM-IV*, which was left uncorrected for 6 years until *DSM-IV-TR* in 2000 was published, the criteria required only one impairment from any of the three core groups. In other words, a PDD-NOS diagnosis could be given in the absence of any social impairment. Although the *DSM-IV-TR* made the presence of social impairments mandatory, the lack of specificity of the criteria make this diagnostic category difficult to apply (Towbin, 2005). In fact, Volkmar and Klin (2000) noted that the *PDD-NOS* diagnosis is often used synonymously with *Asperger’s Disorder*. It is than not surprising that Mahoney and his colleagues (1998) found that expert clinicians’ agreement on the diagnosis of PDD-NOS was no better than chance. As Volkmar and his colleagues (2009) commented, at present, “PDD-NOS remains a source of frustration for parents, clinicians, and researchers alike” (p. 112). The fact that *PDD-NOS* is the most common among autism spectrum disorders (Fombonne, 2005) adds additional weight to the magnitude of the problem.

One consequence of this rather chaotic situation is a possibility that three different clinicians could diagnose the same person with three different conditions: *Autistic Disorder*, *Asperger’s Disorder*, or *PDD-NOS*. Alternatively, the same clinician can give different diagnoses to the same person (Vuletic, Ferrari, & Mihail, 2005). This situation may have serious practical implications because the eligibility for services may depend on the specific diagnosis. Thus, individuals diagnosed with Autistic Disorder may have access to more services than those diagnosed with Asperger’s disorder (Attwood, 2006; Howlin, 2003; Klin & Volkmar, 2000). Moreover, This confusion also has serious consequences for research in that it makes comparisons across studies almost impossible (Ghaziuddin et al., 1992; Klin et al., 2005), thus impeding the progress of further understanding of autism, which, in turn, will impede progress in designing intervention programs.
The *DSM-IV* approach to autism spectrum disorders has also been criticized for being
developmental (Piven, Harper, Palmer, & Arndt, 1996). As already mentioned, the diagnostic
criteria for autism are designed specifically for children older than 3 years of age—ideally
between the ages of 5 and 6—and some of them are not applicable to younger children,
adolescents, or adults. As Piven and his colleagues pointed out, several *DSM-IV* criteria, such as
“lack of varied, spontaneous make-believe play and social imitative play appropriate to
developmental level” (APA, 2000, p. 75), are applicable only for a relatively short age span.
Piven and his colleagues argued that because current criteria do not take into account behavioral
changes that occur during development, initial diagnoses of *Autistic Disorder* might need to be
changed to PDD-NOS later in life simply to account for these changes, when instead the changes
should be regarded as part of the developmental trajectory. Lack of age-graded criteria is
particularly significant in individuals with normal intellectual abilities because they often do not
get diagnosed until adolescence or early adulthood (Barnard, Harvey, Prior, & Potter, 2001;

From the above review, it is already obvious that autism is a highly heterogeneous condition,
that is, it varies with regard to severity and the onset of the core symptoms, age, and the
intellectual level. However, there are two other important sources of variability in the expression
of autism. First, there are a number of difficulties outside the three core areas that often go
together with autism—referred to as “associated features” in the *DSM-IV* to distinguish them
from the core features required for the diagnosis. Examples of these features include unusual
sensory responses (e.g., hypersensitivity to sounds, touch, light or odors, hyposensitivity for
pain, and fascination with certain sensory stimuli), emotional reaction (e.g., absent or
inappropriate reactions), difficulty with attention (e.g., inattention), behavior problems (e.g.,
temper tantrums, aggressiveness, self-injurious behaviors), and motor difficulties (e.g., delayed
motor milestones and motor clumsiness). Second, autism often co-exists with other clinical
conditions (so-called comorbid conditions) such as chromosomal abnormalities, congenital
infections, epilepsy, and psychiatric conditions such as *Attention-Deficit/Hyperactivity Disorder*
(ADHD) and *Depressive Disorders* (APA, 1994, 2000). In fact, research suggests that “pure”
autism (i.e., without additional clinical condition) may not even exist (Gillberg & Billstedt,
2000).
The association of autism with other psychiatric conditions is of special significance for the overall level of functioning and long-term adaptation of autistic individuals. Although the prevalence rates of co-existing psychiatric conditions vary across studies, they commonly range between 65% and 80%, with many autistic individuals having more than one co-existing psychiatric condition (e.g., de Bruin, Ferdinand, Meester, de Nijs, & Verheij, 2007; Ghaziuddin & Zafar, 2008; Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998; Leyfer et al., 2006; Simonoff et al., 2008). For example, in a recent epidemiological study, Simonoff and her colleagues found that 70% of children with autism spectrum disorders had at least one co-existing disorder and that 41% had two or more. In this study, the most common co-existing diagnoses were social anxiety disorder (29.2%), ADHD (28.2%), and oppositional defiant disorder (28.1%). On the other hand, in a sample of adults with autism spectrum disorders, Ghaziuddin and Zafar (2008) found that the most common co-existing disorders were depression and other mood disorders. This latter finding is consistent with the evidence that depression in autistic individuals increases with age (Ghaziuddin et al., 1998; Howlin, 2004). In a recent study, Sterling, Dawson, Estes, & Greenson (2008) found that 43% of autistic adults had depressive symptoms. However, it is important to note that research suggests that rates and types of co-existing conditions vary with the type of autistic disorder. Thus, several recent studies found that the most common co-occurring conditions in children with Autistic Disorder are specific phobias (44%), obsessive compulsive disorder (37%), and ADHD (31%; Leyfer et al., 2006). On the other hand, Ghaziuddin and his colleagues (1998) found that the most common condition in children with Asperger’s Disorder was ADHD (while in adolescents and adults, most common was depression). Yet, de Bruin and her colleagues (2007) found that in children with PDD-NOS, disruptive behavior disorders (61.7%) and anxiety disorders (55.3%) were the most common. All these co-existing psychiatric conditions negatively affect everyday functioning and long-term adaptation of autistic individuals, as well as make psychological research on autism, to which I turn next, much more complicated.

1.1.3 Summary and New Directions

Consistent with the medical model within which it operates, the psychiatric perspective offers a view of autism as a discrete clinical entity defined by an expert consensus as a collection of three
core impairments (i.e., symptoms): (a) impairments in social interaction, (b) impairments in communication, and (c) restricted and repetitive interests and behaviors. However, the view that autism is a discrete entity, qualitatively different from other clinical conditions, as well as from normality, has been recently challenged by genetic studies (Mandy & Skuse, 2008). Given the fact that the DSM-V, which is currently under-development, has adopted a dimensional approach to mental disorders (Regier, Narrow, Kuhl, & Kupfer, 2009) and that the DSM-V workgroups for autism are considering whether a dimensional approach should be taken to diagnosis of autism spectrum disorders (Happé & Ronald, 2008), it is possible that the official psychiatric conceptualization of autism will change with publication of the DSM-V in 2012.

It should be noted that current conceptual problems with regard to autism are not specific to this condition. In fact, they seem to be a major problem across psychiatric conditions. As the leadership of the American Psychiatric Association and the DSM-V Task Force (Schatzberg, Scully, Kupfer, & Regier, 2009) recently commented,

Clinicians complain that the current DSM-IV system poorly reflects the clinical realities of their patients. Researchers are skeptical that the existing DSM categories represent a valid basis for scientific investigations, and accumulating evidence supports this skepticism. Science has advanced, treatments have advanced, and clinical practice has advanced since [the publication of] DSM-IV. The DSM will become irrelevant if it does not change to reflect these advances.

It should also be noted that the current psychiatric perspective does not address the complexity of the individuals it attempts to define, nor the complexity of people’s interactions with and adaptations to their environments (Jensen & Hoagwood, 1997; Jensen, Hoagwood, & Zitner, 2006; Sarbin, 1997; Sonuga-Barke, 1998). In other words, at least according to the critics, the current psychiatric view of autism is very simplistic, static, a development, and decontextualized. In the next section, I consider whether a psychological perspective on autism has been able to correct, or at least modify, this view.

1.2 Psychological Perspectives
Psychological accounts of autism seek to explain the clinical picture given by the psychiatric perspective. In other words, while the psychiatric perspective offers, among other things, descriptions and classification of an observed pattern of behavior, the psychological perspective attempts to understand mental mechanisms that lie behind what is observed. Moreover, based on this understanding, psychological accounts, at least sometimes, even go beyond mechanisms and try to create intervention programs that, ideally, can lead to improvements in symptoms, everyday functioning, and the long-term adaptation of autistic individuals.

Although there have been many attempts to explain autism at the psychological level, as yet, no explanation has gained universal acceptance. Given that most psychological explanations of autism have emanated from the prevailing theoretical approaches of their time, the most influential explanations have been developed within psychodynamic, behavioral, and, most recently, cognitive traditions. I briefly review some of the historically significant proposals put forth so far.

1.2.1 Historical Background

From the early 1940s through to the late 1960s, when autism was first described and was becoming more widely known, psychoanalysis was the prevailing explanatory paradigm for psychopathology in Europe and North America. Quite understandably, then, the initial psychological explanations of autism were influenced by the psychoanalytical perspective on psychopathology.

1.2.1.1 Autism as a Basic Defect of the Ego

Mahler (1952, 1958; Mahler & Furer, 1972) was among the first to offer a psychological perspective on autism. Working within the psychoanalytical tradition, she proposed that autism
was a “basic defect of the ego” (1958, p. 81). According to her theory of child development, every child goes through a stage of “normal autism,” which she described as follows:

Within that twilight stage of early life[,] which Freud designated as primary narcissism, the infant shows hardly any sign of perceiving anything beyond his own body. He seems to live in a world of inner stimuli. The first weeks of extrauterine life are characterized by what (according to Ferenczi) we call the stage of hallucinatory wish-fulfilment. (1958, p. 77)

According to Mahler (1958), after being autistic for two months, infants progress to the next stage of development, which she called a “symbiotic phase” (p. 77). It is the transition to this phase that she posits as the beginning of a pathological autism. Following Freud, she believed that human infants are born with both an “atrophied” (in an evolutionary sense) “instinct of self-preservation” and an immature mental apparatus necessary for independent survival, a combination that makes them completely dependent on “social symbiosis” (p. 77) with their mothers (or other caregivers). She believed that because of “physiological upheaval,” the pathologically autistic infants do not perceive their mothers as being necessary for their survival, thus cannot progress to the next stage of symbiotic development and instead remain “fixated or regress to the autistic phase of extrauterine life or . . . to an even more archaic foetal stage of functioning” (p. 78). She wrote:

In certain cases the severity of the physiological upheaval not only impairs the perceptual activity of the sensorium and thus formation of structure (ego), but even the faculty of primal discrimination (protodiakrisis) between living and inanimate may be lost. Such catastrophic shifts and reactions seem to be the pathogenic agents in early infantile autism. The pivotal disturbance lies in these children’s inability to perceive the Gestalt of the mother and the Gestalt of her vital functioning on their behalf. (p. 77)

For Mahler (1958) then, the roots of autism were in the autistic infant’s perceptual inability to discriminate between animate and inanimate objects and to see “the mother as a living being in particular” (p. 81). She believed that children could either be born with this perceptual inability or they could acquire it: “It is an open question whether this turning a deaf ear toward mother and, consequently, toward the outside world is inborn or an acquired defence” (p. 78). In any

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5 Ego is the key psychoanalytic construct representing a mental structure with integrative functions including perception. Freud posited that the ego was not present at birth and that it develops in the relationship between an infant and a caregiver.
case, she believed, autistic children cannot utilize their mothers as an extension of self and are left to their own immature devises to deal with the overwhelming internal and external stimuli. One way of dealing with them is shutting them out, and, according to Mahler, that is exactly what autistic children do. Thus, for her, the autistic shutting out of the world, and other autistic symptoms, has an adaptive function: “Inability to use the symbiotic partner makes it necessary for these children to find substitute adaptive mechanisms for survival, and these substitutive formations represent the symptomatology of early infantile autism” (p. 78).

Based on this view, Mahler (1952) developed a therapeutic approach which she believed could help autistic children move out of the “autistic shell” (p. 302), as she called the state of autistic children’s withdrawal. Some aspects of her approach, such as following the child’s lead, are still applied in several contemporary interventions for autistic children (e.g., Greenspan, Wieder & Simons, 1998; Kaufman, 1976). However, aside from occasional positive reviews, such as that of Hobson (1990), who not so long ago argued that Mahler’s theory still offers important insights—a point he verified through using some of those insights as a foundation for his own theory (1989, 1993)—Mahler’s work has been largely forgotten. This seems to be attributable, at least in part, to the subsequent characterization of Mahler’s view as psychogenic. Nevertheless, more recent empirical evidence supports Mahler’s key insight about the social perceptual deficits of autistic children (e.g., Blake, Turner, Smoski, Pozdol, & Stone, 2003; G. Dawson, Meltzoff, Osterling, Rinaldi, & Brown, 1998; Jones, Carr, & Klin, 2008; Klin, Lin, Gorrindo, Ramsay, & Jones, 2009; Osterling & Dawson, 1994; Swettenham et al., 1998).

1.2.1.2 The “Refrigerator Mother” Theory of Autism

Contrary to the fate of Mahler’s view on autism, another psychoanalytic theory of autism, that of Bettelheim (1967), is known even to many lay people (Grinker, 2007). It is his theory, known as the “refrigerator mother” theory of autism, that has become representative of the psychoanalytic perspective. However, its roots (but not the gist) could be traced to Kanner and the prevailing zeitgeist in the fields of psychology and psychiatry at the time.
As already mentioned, Kanner concluded his 1943 paper by explicitly rejecting the idea that psychological factors could be the main cause of autism because of its early emergence which he placed at the beginning of life. However, in the same paper, Kanner also made several observations about parents of autistic children, including their high intelligence, obsessiveness, and emotional coldness, and wondered about potential contributions of the pattern of these features to the emergence of autism. For example, he wrote:

In the whole group, there are very few really warmhearted fathers and mothers. For the most part, the parents, grandparents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in people. Even some of the happiest marriages are rather cold and formal affairs. . . . The question arises whether or to what extent this fact has contributed to the condition of the children. The children’s aloneness from the beginning of life makes it difficult to attribute the whole picture exclusively to the type of the early parental relations with our patients. (p. 250)

Although Kanner continued to believe that autism is innate (as he originally stated), the above and similar statements about the parents of autistic children he made over the years6 were taken by Bettelheim (1967) and other proponents of the psychogenic view on psychopathy to the extreme. Like Mahler, Bettelheim saw the disturbance in the symbiosis of the autistic child with the mother to be crucial for the development of autism. However, contrary to Mahler, he attributed the cause of this disturbance not to the child but to the mother. More specifically, he wrote that because autistic children’s central nervous system is “fully developed, certain actions and reactions or the absence thereof are not caused by any lack of potential ability, but by the fact that for some reason a potential was not realized [italics added]” (pp. 4–5). He found this reason in early parental rejection: “The precipitating factor in infantile autism is the parent’s wish that his child should not exist” (p. 125). It should be noted that this view closely echoes the view on the etiology of schizophrenia: At that time, autism was generally considered to be part of childhood schizophrenia (for reviews, see Rimland, 1964, Rutter, 1972). According to the

6 For example, in 1949, Kanner wrote: Most of the patients were exposed from the beginning to parental coldness, obsessiveness, and a mechanical type of attention to material needs only. They were the objects of observation and experiments conducted with an eye on fractional performance rather than with genuine warmth and enjoyment. (p. 425) In addition, several statements attributed to Kanner (which appeared in the popular press) invoked the notion of refrigerator coldness of autistic children’s parents. For example, Kanner was quoted as saying that parents kept autistic children “neatly in a refrigerator which didn’t defrost” (“Frosted children,” 1948), and as describing parents as “just happening to defrost enough to produce a child” (“The child is father,” 1960).
infamous “schizophrenogenic mother” theory, the schizophrenic individual is “painfully distrustful and resentful of other people because of the severe early warp and rejection [italics added] that he encountered in important people of his infancy and childhood, as a rule, mainly in a schizophrenogenic mother” (Fromm-Reichmann, 1948, pp. 163–164).

According to Bettelheim, autism emerges when the child’s actions evoke negative response from the mother, to which “the child responds with massive withdrawal” resulting in a “chronic autistic disease” (p. 126). Although his theory is known as a theory of the “refrigerator mother,” Bettelheim (1967) did not use the phrase; however, the name fits his description of mothers of autistic children. In accord with his views of autistic children’s mothers, Bettelheim recommended that the best treatment for autistic children was to separate them from their inadequate mothers and place them in institutions.

Although research failed to support Bettelheim’s theory (e.g., Cantwell, Baker, & Rutter, 1978; Rimland, 1964; and more recently, Doussard-Roosevelt, Joe, Bazhenova, & Porges, 2003; van IJzendoorn et al., 2007), the devastating consequences of this theory for parents of autistic children could not be easily erased (Eberhardt, 1967; Grinker, 2007). Nevertheless, Kanner’s (1943, 1949), Asperger’s (1944/1991), and others’ early observations about personality characteristics of autistic children’s parents (for a review, see Rimland, 1964) have stood the test of time (Bolton et al., 1994; Murphy et al., 2000; Piven et al., 1997; Piven, Wzorek, Landa, & Lainhart, 1994; Wolff, Narayan, & Moyes, 1988). However, these observations are now interpreted, as Asperger (1944/1991) suggested, as an indicator of a genetic etiology of autism.

### 1.2.1.3 The Behavioral Approaches to Autism

During the 1960s, in parallel with the psychogenic view on autism, a new, behavioral, approach to autism started to emerge. Ferster (1961) was the first to use learning theory (that of B. F. Skinner, 1953) to explain autism. He suggested that autistic behavior was the result of environmental conditioning. Consequently, he suggested, the behavior of autistic children, like all behavior, could be altered by changing environmental reinforcements. Indeed, many subsequent studies reported a variety of positive changes in autistic children using behavior
modification techniques that employed a variety of reinforcers including electric shocks (Lovaas, Schaeffer & Simmons, 1965), slaps, time-outs, and rewards such as praise and food (Lovaas, 1987; Lovaas et al., 1981).

Building on observations of autistic children’s behavior in therapeutic environments, Lovaas and Smith (1989) have proposed the most elaborate behavioral theory of autism so far. According to their view, autism is not an entity (i.e., there are no behaviors, neurological or psychological structures that are unique to it), as usually assumed, but only a hypothesis—and “a poorly supported” one (p. 19) at that. They supported this claim citing the wide range of individual differences observed among autistic children in a variety of domains (including different responses to treatment) and the fact that all of the so-called autistic behaviors also exist in non-autistic individuals. Instead, they suggested that autistic children have many separate behavioral difficulties (not one, as usually assumed by theories of “core deficit”) and that they are best described as developmental delays that can be explained by the laws of learning. They further believed that autistic children’s difficulties arise from “a mismatch between their nervous systems and the normal environment” (p. 24). Consequently, they believed that autistic children cannot learn in typical environments and that, in order to learn, they need special environments.

Published reports of autistic children’s learning in these special (i.e., very structured) environments partly support this claim. For example, Lovaas (1987) reported that after a minimum of 2 years of a one-on-one treatment for at least 40 hours a week, nearly half of the children in the experimental group (9 out of 19 children) achieved “normal intellectual and educational functioning” (p. 3). Moreover, McEachin, Smith and Lovaas (1993) reported that these gains were maintained after 3 to 9 years. Although many subsequent studies have confirmed improvements in multiple areas following the treatment (e.g., Eikeseth, Smith, Jahr, & Eldevik, 2002; Harris, Handleman, Gordon, Kristoff, & Fuentes, 1991; Sallows & Graupner, 2005; Sheinkopf & Siegel, 1998), and several recent reviews suggest that this treatment appears to be the best one currently available (Eldevik et al., 2009; Howlin, Magiati, & Charman, 2009; S. J. Rogers & Vismara, 2008), it is only rarely reported that it leads to the “recovery” from autism. Instead, Howlin and her colleagues (2009) recently concluded that more often it results in only modest, little or no change. This lack of greater improvement following the treatment diminishes the validity of theoretical explanations.
1.2.2 Contemporary Views: The Basic Cognitive Deficit Theories of Autism

During the 1970s, the emergence of cognitive psychology, with its focus on information-processing and experimental research methods (Gardner, 1985) brought new directions in psychological research and theorizing on autism. Since this time, it has been generally accepted that autism is a consequence of “a basic cognitive deficit” (Rutter, 1983, p. 513). According to Rutter (1983), “the problem [of autism] is one of an inherent inadequacy in the child’s cognitive equipment” (p. 561). Consequently, one of the most important research questions is to find “what cognitive deficits must [italics in original] be present for autism to develop” (p. 521). Accordingly, various aspects of cognition were put forward as “core” or primary deficits able to explain all other impairments of autism. Some of the earliest cognitive models of autism include language/perception (Rutter, 1968; Rutter & Bartak, 1971), perception (Hermelin & O’Connor, 1970), memory (Boucher & Warrington, 1976; Rimland, 1964), and attention (Lovaas, Koegel, & Schreibman, 1979) deficit hypotheses.

These cognitive hypotheses generated extensive research (for reviews, see, DeMyer, Hingtgen & Jackson, 1981; Prior, 1979; Prior & Ozonoff, 2007). However, although there is now evidence of the existence of deficits in all proposed cognitive domains—attention (Allen & Courchesne, 2001), perception (P. Mitchell & Ropar, 2004), memory (Bennetto, Pennington, & Rogers, 1996; D. L. Williams, Goldstein, & Minshew, 2006), and language (Tager-Flusberg, Paul, & Lord, 2005)—this evidence does not support any of the claims for the core deficit. That is, it does not answer the main question posed by Rutter (1983) about the conditions that are necessary and sufficient for autism to occur. Importantly, no intervention programs grew out of the early cognitive models of autism. It should be noted that some non-cognitive accounts of autism have also been proposed. For example, building on psychoanalytical tradition, Hobson (1989, 1993) proposed that the primary deficit in autism is in the domain of interpersonal relatedness, a domain that encompasses emotions, cognition, and action.
From the mid 1980s until the present, three deficit theories dominated research and theorizing on autism: the theory of mind, executive function, and central coherence deficit hypotheses of autism (for recent reviews, see Hill & Frith, 2003; Rajendran & Mitchell, 2007; Volkmar et al., 2004). Next, I briefly review these models of autism and the research and interventions they inspired.

### 1.2.2.1 The Theory of Mind Deficit Hypothesis

According to the theory of mind deficit hypothesis (also known as mindblindness hypothesis), the core psychological impairment in autism involves an inability to attribute mental states (such as intentions, desires, and beliefs) to self and others (Baron-Cohen, 1995; Baron-Cohen, Leslie, & Frith, 1985). This claim, originally based on experimental findings that 80% of autistic children fail a false belief task at the age it is typically passed by non-autistic children (4 years) has been (partly) supported by many replication studies using a variety of false belief and other “mentalizing” tasks such as understanding pretence, irony, and deception (for a review, see Baron-Cohen, 2000b). However, the fact that at least some autistic children (20% in the original study; and 15–60% in other studies; Happé, 1994) do pass the theory of mind task puts a limit to the explanatory power of this theory. The subsequently modified “deficit hypothesis” (referred to as a “delay hypothesis”; Baron-Cohen, 1989a), which proposed that although some autistic children can pass the most basic, so-called first-order theory of mind tasks, they cannot pass more advanced, second-order tasks, has also been challenged. For example, Bowler (1992) found that at least some autistic individuals could pass even the second-order theory of mind tasks. Frith and her colleagues hypothesized that autistic individuals who pass the theory of mind tasks do so based on learning and reasoning (i.e., extracting rules from experience), not intuition, as normal children do (Frith, Morton, & Leslie, 1991). In other words, individuals who pass the theory of mind tasks may do so by “hacking” the solution, not by “mentalizing” (Frith, Happé, &

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7 A standard false belief task (also referred to as the first-order theory of mind task, and the task used in this first study) could be summarized as asking, “Where will Sally look for her marble after Ann has moved it in Sally’s absence?”

8 While the first-order theory of mind task asks, “What does Sally think,” the second-order theory of mind task asks, “What does John think Mary think?”
Siddons, 1994, p. 110), and they may still lack an “intuitive theory of mind” but may have an “explicit theory of mind” (acquired through learning; Frith, 1997).

The theory of mind deficit hypothesis of autism has been criticized on additional grounds. First, Happé (1994) and others argued that it cannot account for all symptoms of autism, in particular, stereotyped behavior and restricted interests. Second, Hobson (1993), Klin and Volkmar (1993), and others argued that the deficit in the theory of mind may not be the primary deficit in autism because autistic symptoms emerge before the theory of mind emerges at the age of four. Third, a deficit in the theory of mind is not specific to autism because it is also found in other atypical populations, such as in deaf children (C. C. Peterson & Siegal, 2000) and people with mental retardation (Yirmiya, Erel, Shaked, & Solomonica-Levi, 1998). Fourth, the theory is inadequate to explain autism because autistic children are not impaired in all aspects of theory of mind. For example, research evidence suggests that autistic children have adequate understanding of seeing and wanting (Tan & Harris, 1991) and atypical emotions (i.e., those that are not expected in the situation, such as being sad after receiving a present; Rieffe, Meerum Terwogt, & Stockmann, 2000) and that they can adequately monitor goal-directed actions (Russell & Hill, 2001; for a review of other challenges to the theory of mind theory, see Rajendran & Mitchell, 2007).

In response to some of the criticism, Baron-Cohen has repeatedly revised, and thereby weakened, his original claim of the theory of mind deficit hypothesis several times. For example, he admitted that the deficit in the theory of mind “is not the only cognitive deficit in autism” (Baron-Cohen & Swettenham, 1997, p. 885) and that it could co-occur with other deficits, such as weak central coherence and executive dysfunction. More recently (2002, 2003), he added a new factor, “systemizing” (which refers to a drive to analyze and construct systems), to the theory of mind factor (now renamed “empathizing”). This change led to his current empathising-systemising hypothesis. In the new theory, “system” refers to “anything that takes inputs and deliver [sic] outputs” (2002, p. 248) and includes technical, natural, social, and any other systems.) According to this theory (which tries to account for some of the strengths associated with autism, such as unusual talents, high attention to detail, all-absorbing interests in special topics, and collections of facts about those topics), autistic individuals still have a core deficit in the theory of mind and, in addition, a hyper-developed drive to systemize. However, although this new theory can explain “higher” aspects of behavioral impairments (i.e., specific interests),
it cannot explain its “lower” forms, such as repetitive and stereotyped behavior (e.g., hand flapping in front of the eyes and toe walking).

The original theory of mind model of autism served as the basis for several training programs aimed at teaching autistic children elements of the theory of mind (e.g., Baron-Cohen, Golan, Wheelwright, & Hill, 2004; Howlin, Baron-Cohen, & Hadwin, 1999). Unfortunately, several of these training studies (using a variety of programs) did not produce particularly encouraging results. For example, although teaching theory of mind did improve performance on the particular tasks the children were trained on, gains did not generalize to other theory of mind tasks (Hadwin, Baron-Cohen, Howlin, & Hill, 1997; McGregor, Whiten, & Blackburn, 1998), nor did the training improve social competence in everyday life (Ozonoff & Miller, 1995), nor the performance on relevant tasks of communication (Hadwin et al., 1997), pretence (Hadwin, Baron-Cohen, Howlin, & Hill, 1996) and executive function (Fisher & Happé, 2005). This poor generalization to other areas of functioning further weakens the claim of a primary deficit in theory of mind in autism.

Although neither the original theory of mind hypothesis nor its subsequent modifications, including the empathising-systemising hypothesis (Baron-Cohen, 2002, 2003), have been able to explain the full phenomenon of autism, this theory is still among the most prominent hypotheses available (Rajendran & Mitchell, 2007; Volkmar et al., 2004). And although the available evidence does not support the theory’s main claim that a deficit in theory of mind is the core deficit in autism, this hypothesis has provided important evidence about the social cognition of autistic individuals (for a review of this evidence, see Hill & Frith, 2003). In addition, it has provided testable hypotheses for neuroscientific research, thus advancing our understanding of the possible neural underpinning of autism (for a review of this evidence, see Hill & Frith, 2003; Volkmar et al., 2004).

1.2.2.2 The Executive Dysfunction Hypothesis

The second, currently major, hypothesis of autism is the executive dysfunction hypothesis (Ozonoff, 1995; Ozonoff, Pennington, & Rogers 1991). The executive function refers to the
ability to plan and execute complex behavior; it also includes inhibition of a pre-potent response, impulse control, working memory, problem-solving related to future goals, and flexibility of thought and action (Hill, 2004). The main claim of this hypothesis is that the executive functions in autistic persons may be “uniquely impaired” (e.g., Ozonoff, 1995, p. 200)—a claim based on common findings that autistic subjects have poor performance on psychological tasks requiring executive functions. (Executive functions are usually measured by neuropsychological tests, such as the Wisconsin Card Sorting Test that require conceptual problem solving; for a test description, see Pennington & Ozonoff 1996.)

The available empirical evidence (almost 150 articles over the past 30 years; Kenworthy, Yerys, Anthony, & Wallace, 2008) provides mixed support for the executive dysfunction hypothesis (for recent reviews, see Hill, 2004; Kenworthy et al., 2008; Rajendran & Mitchell, 2007). First, the evidence suggests that not all executive functions are impaired in autism. The most commonly impaired functions are flexibility and planning, while inhibition is usually unimpaired (Kleinhans, Akshoomoff, & Delis, 2005; Ozonoff & Jensen, 1999). Second, not all autistic individuals are impaired on executive function tasks (Liss et al., 2001; Pellicano, Murray, Durkin, & Maley, 2006). For example, only half of the participants in the study conducted by Pellicano and her colleagues had difficulties on executive function tasks. Third, impairments in executive function are not specific to autism; they are also found in attention deficit hyperactivity disorder, conduct disorder, Tourette syndrome, and other clinical conditions (for reviews, see Baron-Cohen & Swettenham, 1997; Sergeant, Geurts, & Oosterlaan, 2002).

Despite the interest in the executive functions in autism, only one published study (Fisher & Happé, 2005) investigated the effectiveness of training program aimed at teaching them to autistic children. This study reported no improvement in performance on executive function tasks following the training but, ironically, a significant improvement in performance on theory of mind tasks, which weakens the “core deficit” claim of the executive dysfunction hypothesis.

1.2.2.3 The Weak Central Coherence Hypothesis
The main claim of the third major cognitive theory of autism, the weak central coherence hypothesis, is that the core deficit in autism is an inability to process information globally, instead favoring local processing (Frith, 1989; Frith & Happé, 1994). According to this theory, autistic individuals are deficient in the ability to “draw together diverse information to construct higher-level meaning in context” (Frith & Happé, 1994, p. 121). This claim was originally supported by evidence from two lines of research. On the one hand, autistic individuals were found to have superior performance on tasks that favor local processing (e.g., on the Embedded Figures Task and the Block Design subtest of the WISC; Shah & Frith, 1983; Shah & Frith, 1993). On the other hand, autistic individuals were also found to have poor performance on tasks that require the integration of information into a coherent whole (Frith & Snowling, 1983).

However, subsequent research evidence in support of this hypothesis is mixed (for recent reviews, see Happé & Frith, 2006; Rajendran & Mitchell, 2007). In general, this evidence supports the claim of local preference—now rephrased as superiority in tasks that favor local processing (e.g., Pellicano et al., 2006)—but fails to confirm impaired global processing in autism (e.g., Lopez & Leekam, 2003; Mottron, Burack, Stauder, & Robaey, 1999; Plaisted, Swettenham, & Rees, 1999). In an attempt to accommodate these recent empirical findings, Happé (1999) and Happé and Frith (2006) modified the original “core deficit” hypothesis and proposed that superior local-inferior global information processing is a “cognitive style,” not a core deficit in central processing; that is, the difficulties autistic people experience with global processing can be overcome if such processing is explicitly demanded. Furthermore, Happé and Frith suggested that the failure in global processing is not a primary but, rather, a secondary problem and is only one aspect of autistic cognition—not a “core” deficit that could explain other impairments associated with autism—thus diminishing the original explanatory power of the hypothesis.

There have been no published reports about applying this theory in interventions for autistic children, and its major contribution lies in generating new knowledge about autistic cognitive style. In addition, this theory should be credited with its pioneering attempt to account for both the strengths and weaknesses associated with autism.
1.2.3 Summary and New Directions

Psychological theorizing and research on autism have generally focused on identifying its core deficits and on defining its distinctness from other developmental disorders and from typical development. Although these efforts identified numerous areas of attentional, cognitive, social, and emotional impairments associated with autism, they have not provided a clear picture of the mental mechanisms behind autism nor have they answered the question posed by Rutter (1983) about the necessary and sufficient conditions for the emergence of autism.

Like the literature on the psychiatric perspective on autism, the literature on the psychological perspective is characterized by conflicting views and research findings: research inconsistencies are almost the rule rather than the exception (see, for example, Kenworthy et al., 2008; Vuletic et al., 2005). One possible reason for such confusion might lie in the psychiatric descriptions of autism, on which the psychological research relies. For example, there may be even more heterogeneity in autism than is currently recognized by the *DSM-IV*.

The psychological perspective still views autism as a single deficit; however, there may be more than one core deficit in autism. This possibility has already been alluded to by Happé and Frith (2006, and previously suggested by R. Goodman, 1989, Lovaas & Smith, 1989, and, more recently, Baron-Cohen & Swettenham, 1997). In fact, Happé, Ronald, and Plomin (2006) recently proclaimed that “there will be no single (genetic or cognitive) cause for the diverse symptoms defining autism” and that it is “time to give up on a single explanation for autism” (p. 1218). Moreover, there is some empirical support for this proposal (Pellicano et al., 2006). If so, one way to move away from the current diagnostic confusion and psychological impasse would be to change the methodology currently used in both psychiatric and psychological research which, for the past four decades, has relied almost exclusively on cross-sectional group comparison and correlation methods. As Rajendran and Mitchell (2007; see also Vuletic et al., 2005) have suggested, one useful, but almost forgotten, approach in confusing situations like this is to conduct detailed case studies. This is the method I propose to use in this project.

Finally, although research conducted from the deficit model perspective has been valuable for understanding the differences between autistic and non-autistic individuals, it fails to adequately
explain autism or the unique developmental paths of autistic individuals, nor does it provide useful guidance for interventions (Sigman, Spence, & Wang, 2006). Most importantly, it fails to understand autistic individuals as multidimensional persons with unique life experiences, personalities, values, and hopes—precisely the concern of this current study.

1.3 Parental Perspectives

Note. In this thesis, to distinguish personal (parental and first-person) from professional perspectives, I use both first and last names when referring to the former.

Parents’ accounts of autism have been available since 1967, when Frances Eberhardy and Clara Park published the first two biographical accounts of their children. These accounts present a view of autism as a human, not medical, condition. From the perspective of those living with autistic individuals, those who “have been there, morning, noon, and night, experiencing [it]” (Park, 1986, p. 82), autism is all about an imbalance of exaggerated human features—both positive and negative.

For their parents, autistic individuals are, first and foremost, thinking and feeling human beings with unique personalities, strengths and weaknesses—although with a larger than average share of weaknesses (Cutler, 2004; Dewey, 1991, 1992; Fling, 2000; Gernsbacher, 2004a, 2004b; Grinker, 2007; Mont, 2002; Moore, 2004; Park, 1967, 1983, 1986, 2001). In their biographical accounts, parents of autistic individuals wrote about their children’s unique ways of experiencing the world, their lack of social responsiveness and intuition, their difficulties with learning social skills, and their fears and anxieties, as well as about their “individuality and charm” (Park, 1983, p. 286), intelligence, wittiness, sense of humor, exceptional memory, honesty, innocence, affection, beauty, and lovability. They emphasize their special abilities—in math, science, art, or music—and are fascinated with their logicality and creativity (“autistic thinking”) and find them to be “non-malevolent, unworldly, handsome, and intriguing” (Moore, 2002, p. 281). They admire their bravery and persistence in facing and learning about the ways of the world for which they were born unequipped.
Moreover, even when writing about their children’s problems, parents use a nonjudgmental vocabulary: they write about “unique” ways of interacting with others (Fling, p. 54), “marching to [their] own drummer” (Gernsbacher, 2004b, p. 83), “rage for order” (Park, 1967), and “autistic eccentricity” (Dewey, 1992). They see their autistic children as just “different” from others. For example, the mother of twelve-year-old Teodor described her son’s social needs as “different” from hers when she was his age:

I was very much interested in being in a group while he’s not. I wanted very much to have friends; well, this is not his main priority. If he has friends—that’s fine, if he doesn’t—that’s fine. He’s not looking for friends while I was. And he won’t like being in a group and doing whatever everybody would do—he would want to do his stuff. And he doesn’t want to be popular. He doesn’t want to be dressed in certain clothes. This is not one of his problems. (Vuletic et al., 2005, p. 23)

Likewise, Teodor’s father also notices just the “difference”:

He is somehow different from the other children because he likes to live how he likes, and if this kind of living is in contradiction with what all the other children are doing, he’s trying to go on his way. (p. 26)

However, Teodor’s mother added, as if to balance out the above-described social differentness, that in some situations Teodor could be “very understanding towards other people—other people’s problems” (Vuletic et al., 2005, p. 23). For example, if a friend is hurt, he would try to help: “He would come home, get the band-aid, go there, take care, and just try to help” (p. 23). Moreover, she emphasized that despite Teodor’s disinterest in his peers, he “really loves his family” and is “really well related to the family” (p. 22).

Such tendency toward balancing highs and lows, strengths and weaknesses, “virtues and defects” (Park, 1986, p. 98) is present in all biographical accounts. As Morton Ann Gernsbacher (2004a) described her eight-year old son, “his strengths are astounding, and his weaknesses are heartbreaking. The only average thing about him is his height and weight.” This is an important legacy of the parental perspective because, until recently, the professionals offered mostly unidimensional views of autism that see only impairments and deficits (Gernsbacher, 2004a; Moore, 2008). According to parents, such views paint a picture of an autistic person as a “collection of symptoms, not as an individual” (Moore, 2008, p. 493).
Moreover, some parents of autistic children explicitly argue against the prevailing professional and public view that autism is a disorder or illness (Cutler, 2004; Gernsbacher, 2004a). For example, based on her review of family members across several generations, Eustacia Cutler (2004) suggested that “autism isn’t an exotic disorder, out there somewhere on its own. . . . Autism is an exaggeration of what lies in us all” (p. 164). Moreover, taking into account wishes of some autistic individuals (to be described next), Morton Ann Gernsbacher (2004a) suggested that “autistics don’t want to be cured; they want to be accepted” and invited the public to “celebrate diversity, to appreciate human variation, and to marvel at determined focus” of autistic individuals.

1.3.1 Summary

Parental perspectives add more complexity, balance, and humanity to the picture of autism. As such, they resemble the initial clinical accounts of Kanner (1943) and Asperger (1944/1991)—which were, in part, based on parental accounts—more than those of professionals today (although, as reviewed above, at least some of these accounts have recently started to change). In fact, Asperger’s account of autism is very similar to those of autistic children’s parents in that his portraits of autistic children emphasized not only peaks and valleys, but also the quantitative, not qualitative, differences between autistic and typical individuals—a point also strongly made by autistic people themselves, whose perspectives on autism are reviewed next.

1.4 First-Person Perspectives on Autism

In this thesis, I have considered autobiographical accounts of 73 autistic individuals (age range, 10 [Hale, 2001] to 57 [Schneider, 1999]; the majority was between 25 and 45 years of age, and only three were under 20 [Hale, 2001; L. Jackson, 2002; N. Jackson, 2002]; countries of origin include Australia, Belgium, Canada, Finland, Netherlands, Sweden, UK, and US). I made all possible effort to only include perspectives of individuals who have stated that they have been diagnosed with autism and who either provided names of the professionals who diagnosed them
or for whom there exist other independent sources that corroborate their statements about their diagnosis (e.g., references to, forwards, epilogues or blurbs made by professionals in the field of autism). The following 83 sources were reviewed: book-length autobiographies (30); chapters in edited books (19); guides and other books in which autistic individuals described their experiences to illustrate and support their perspectives (12); journal articles (10); websites (6); conference presentations (3); anthologies of autobiographical accounts of autistic individuals (2); and a book of poetry (1). (Because accounts of several individuals appear in more than one source, there are more sources than individuals.)

From the perspective of those who know what autism is most intimately—as they have been living it—autistic individuals describe autism as a complex human condition with advantages and disadvantages (e.g., Barron & Barron, 1992; Boswell, 2008; Dakin, 2005; Dumortier, 2004; Fleisher, 2003; Gerland, 1997; Grandin, 1984, 1992, 1995a, 1995b, 1995c; Grandin & Scariano, 1986; Grandin & Barron, 2005; Hale, 2005; Hammerschmidt, 2008; Holliday Willey, 1999, 2001; L. Jackson, 2002; N. Jackson, 2002; Jansen, 2005; Jolliffe et al., 1992; Lawson, 2000, 2003; Lissner, 1992; McKeen, 1994, 1998; Miedzianik, 1986; Newport, 2001; Peers, 2003; Prince-Hughes, 2002, 2004; Purkis, 2006; Robison, 2008; Sainsbury, 2000; Schneider, 1999; Shore, 2001; Spicer, 1998a, 1998b; Tammet, 2006; D. Williams, 1992, 1994, 1996a, 1996b, 1998, 2004a, 2004b). They address some of the same issues discussed in professional and parental literature: social and communicative difficulties (e.g., difficulty understanding unspoken social rules and nonverbal communication, difficulty using non-verbal communication including eye contact, expressing emotions, and forming relationships) and the need for predictability and routines. However, they assign different meaning to these issues.

Autistic individuals emphasize different aspects of autism than the professionals. More specifically, they often (although not always) emphasize the peculiarities of their sensory processing. This includes both hypersensitivity (more often) and hyposensitivity, in all sensory domains (e.g., Gerland, 1997; Grandin, 1984, 1995c; Grandin & Scariano, 1986; Holliday Willey, 1999; N. Jackson, 2002; Jolliffe et al., 1992; McKeen, 1994; Prince-Hughes, 2004; D. Williams, 1992, 1994, 1996a; for a recent review, see Chamak, Bonniau, Jaunay, & Cohen, 2008; see also Vuletic et al., 2005). For example, in one of the first autobiographical accounts of an autistic individual, Temple Grandin (1984) described her hypersensitivity to noise: “The noise
and confusion at birthday parties disturbed me as a young child. The party noise was like a great
massive wave of confusion. At parties I often became upset and had a tantrum” (pp. 155–6). Later, in her autobiographical book (Grandin & Scariano, 1986), she wrote,

Thanksgiving and Christmas was even worse. . . . The clamour of many voices, the
different smells—perfume, cigars, damp wool caps or gloves—people moving about at
different speeds, the constant noise and confusion, the constant touching, were
overwhelming. (p. 21)

For Temple Grandin, “Loud noises were also a problem, often feeling like a dentist’s drill hitting
a nerve. They actually caused pain” (Grandin & Scariano, 1986, p. 67). When she was young, Temple was also hypersensitive to touch: “I could barely tolerate being touched, and I would
stiffen up, flinch, and jerk away” (p. 151).

Gunilla Gerland (1997) was also hypersensitive to many sensory stimuli. She described her
sensitivity to light touch:

To be just lightly touched appeared to make my nervous system whimper, as if the nerve
ends were curling up. If anyone hit on the terrible idea of tickling me, I died. It was so
way beyond unbearable unbearableunbearableness that I simply died—or that’s what it felt like. (p. 38)

For Gunilla Gerland (1997), touching some objects was also overwhelming. She wrote,

I had—and always had had, as long as I could remember—a great fear of jewelry. That
terror also included hairclips and metal buttons. I thought they were frightening,
detestable, revolting. If I was made to touch jewelry, I felt a sharp whistling metallic
noise in my ears, and my stomach turned over. Like a note falsely electrified, that sound
would creep from the base of my spine upwards until it rang in my ears, tumbled down
into my throat and settled like nausea into my stomach. (p. 54)

Moreover, autistic individuals suggest that their repetitive, ritualistic, and stereotyped behavior
(described from the third-person perspective as “odd,” “weird,” and “bizarre” behaviors) are
their way to cope with the sensory “overload.” For example, Temple Grandin (1995) made the
following observation:

Rocking and spinning were other ways to shut out the world when I became overloaded
with too much noise. Rocking made me feel calm. It was like taking an addictive drug.
The more I did it, the more I wanted to do it. My mother and my teachers would stop me so I would get back in touch with the rest of the world. (pp. 44–45)

Similarly, Therese Jolliffe (Jolliffe et al., 1992) sees the routines and rituals she developed as strategies for coping with the overwhelming confusion of everyday sensory stimulation:

Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seems to be no clear boundaries, order or meaning to anything. A large part of my life is spent trying to work out the pattern behind everything. Set routines, times, particular routes and rituals all help to get order into an unbearably chaotic life. Trying to keep everything the same reduces some of the terrible fear. (p. 16)

On the other hand, autistic individuals have also described certain types of sensory stimuli as sources of joy. For example, Sean Barron (Barron & Barron, 1992) wrote, “I loved the texture of chains. Each link looked the same and even felt the same as all the others” (p. 31). Liane Holliday Willey (1999) described her joy from reading the dark print so neatly typed on the white pages. I enjoyed the rhythmic pattern and the flow that moved the eye from left to right, from top to bottom. I welcomed the routine that insisted I stop for periods and break for commas and new paragraphs. I loved the way most words played on my tongue. I loved the way they caused different parts of my mouth to move. (p. 24)

Temple Grandin (1995) even used the word “trance” to describe the joy she got from her “play” with the sand when she was young:

I could sit for hours on the beach watching sand dribbling through my fingers. . . . As I scrutinized their shapes and contours, I went into a trance which cut me off from the sights and sounds around me. (p. 44)

Likewise, Dawn Prince-Hughes (2004) talked about the “physical thrill” she gets at the sight of symmetry: “I love driving through tunnels and being surrounded by their roundness” (p. 2).

Like their parents (but unlike professionals), autistic individuals also emphasize their personality characteristics such as a strong sense of justice, honesty, and perseverance (e.g., McMullen, 2000). They take pride in their loyalty, tenacity, and eagerness to learn (e.g., Holliday Willey, 2001). They also value the fact that they are trustworthy, dependable, and committed (e.g., Lawson, 2008b). Interestingly, the behaviors behind all these traits are the same ones described
in professional literature as impairments in social interaction. For example, honesty is among the most highly valued traits—almost universally mentioned—by autistic individuals. However, for professionals, expressing one’s view honestly, regardless of context, is an indicator of a pathological lack of social sensitivity.

This fundamental difference in perspective has puzzled autistic individuals. For example, Gunilla Gerland (1997) wrote, “I always said exactly what I meant, neither more nor less. That other people didn’t do that was very confusing” (p. 35). Liane Holliday Willey (1999) made the following observation:

> Sometimes people want an opinion, sometimes they do not. Sometimes they say something so incredible an opinion has to be given. . . . The entire dichotomy is too confusing. I do not see how anyone can ever know with any degree of certainty when they should voice their thoughts and when they should keep them silent. (p. 32)

However, she insists that being honest is the right way to be, “But when we are accused of being blunt and rude because we have provided an honest assessment and straightforward answer to a problem, we sit misaccused and misunderstood” (p. 18). On the other hand, Donna Williams (1998) believes that she has found both the source and solution for the discrepancy:

> Society appears to promote honesty but most of its structures rely on dishonesty. . . . It is about the world of “appear” and about game playing in which one presents the “appear” under the guise that it is the “be”. (p. 111)

In Donna’s view (Williams, 1998), the dichotomy between “the be” and “the appear” stems from two different systems of knowing, instinctual sensing and cognitive interpretation, respectively. According to her, instinctual sensing (the system of children and autistic people) is a natural way that leads to honesty, while interpretation (the system of non-autistic people), which leads to—sometimes necessary—dishonesty, needs to be learned. Because she believes that both systems have their advantages and disadvantages, she “became ‘bilingual’ in acquiring and becoming reasonably able to use the system of interpretation as well as the system of sensing” (p. 111)—in other words, she learned to be dishonest, if necessary, without losing her ability to be honest (which, she suggests, usually happens with non-autistic people).
Like their parents, the majority of autistic individuals who published their autobiographies also express the pride and/or joy they get from their abilities, skills, talents, and accomplishments. Most often mentioned talents include mathematics (e.g., Fleisher, 2003; Newport, 2001; Tammet, 2006), arts (e.g., Purkis, 2006; D. Williams, 1994, 1996a, 2004b), music (e.g., McKeen, 1994; Shore, 2001; D. Williams, 1994, 1996a, 2004b), design (e.g., Grandin, 1984, 1995c; Robison, 2008), poetry (e.g., McKeen, 1994; Miedzianik, 1986; Prince-Hughes, 2004; D. Williams, 1994, 1996a, 2004b), and creative writing (e.g., Holliday Willey, 1999; N. Jackson, 2002; Jansen, 2005; Mór, 2007; Nazeer, 2006; Peers, 2003). Autistic individuals also find joy in using their exceptional memories (e.g., Fleisher, 2003; Grandin, 1995c; Tammet, 2006) and engaging in intellectual pursuits (Grandin, 1995c; Schneider, 1999; Tammet, 2006).

Many autistic individuals also wrote about the joy they get from successful social relationships (e.g., Dumortier, 2004; N. Jackson, 2002; Lawson, 2008b; McKeen, 1994; Prince-Hughes, 2004; Tammet, 2006; D. Williams, 1992, 1994, 1996b, 2004a). Likewise, many autistic individuals also expressed profound feelings of loneliness during periods when they did not have such relationships (e.g., Fleisher, 2003; Jansen, 2005; N. Jackson, 2002; Miedzianik, 1986; Prince-Hughes, 2004; Tammet, 2006). Importantly, feelings of loneliness did not always come from not having friends or partners; rather, it seems that at least for some autistic individuals they stem from a profound feeling of being different from others. For example, despite having several “close friends” and a boyfriend, Dominique Dumortier (2004) wrote that she is “terribly lonely” (p. 96). She once commented, “I felt misunderstood and let down. I felt I was so different and that I spoke another language” (p. 7). Her profound feeling of differentness and loneliness led her to conclude pessimistically: “I will always feel different. I am alone, quite alone, and that hurts. The wall cannot come down. It stays there. Forever” (p. 95).

On the other hand, several autistic individuals, either explicitly or by implication, suggested that loneliness is not part of their lives. For example, Edgar Schneider (1999) wrote, “I have never felt lonely or a need for what could be called ‘the warmth of another human being’, even a loving woman, or a good friend of either sex” (p. 57). John Smith Boswell (2008) expressed the same sentiment:
While growing up, people were never my first priority, and I still think this statement is true. In kindergarten, I would eat my lunch and then stare out the window at other kids playing. I had my first and last girlfriend in first grade. (p. 354)

Temple Grandin (1995c) explained how she meets her social needs through professional contacts:

I know that things are missing in my life, but I have an exciting career that occupies my every waking hour. Keeping myself busy keeps my mind off what I may be missing. Sometimes parents and professionals worry too much about the social life of an adult with autism. I make social contacts via my work. If a person develops her talents, she will have contacts with people who share her interests. (p. 139)

Autistic individuals also write about their frustrations, sadness, emotional pains, fears, anxieties, panic attacks, and depression that come from living with autism (e.g., Andrews, 2006; Barron & Barron, 1992; Dakin, 2005; Dumortier, 2004; Gerland, 1997; Grandin, 1995c; Grandin & Barron, 2005; N. Jackson, 2002; Jansen, 2005; Jolliffe et al., 1992; Lawson, 2000; McKean, 1994; C. Mitchell, 2005; Prince-Hughes, 2004; Sainsbury, 2000; D. Williams, 1992, 1994, 1996b, 1998). As Dominique Dumortier (2004) put it, “Living with autism hurts a lot, especially when you are with other people who are not autistic. Because they provide such a big contrast they make the pain so much worse” (p. 93).

Another common thread among autobiographical accounts is the active “fight” against the “negative” traits of autism. Many autistic individuals described resisting their autistic instincts, “habits,” and natural ways, and consciously learning and implementing “mainstream” social behavior and “acting normal,” as will be discussed in the next section (Barron & Barron, 1992; Grandin & Scariano, 1986; Dumortier, 2004; Holliday Willey, 1999; D. Williams, 1996a, 1996b). Autistic individuals also describe the physical and emotional “cost” of effortful everyday living (Gerland, 1997; Dumortier, 2004; Holliday Willey, 1999; McKean, 1994; Prince-Hughes, 2004; Spicer, 1998a, 1998b; D. Williams, 1996a, 1996b, 1998). They describe how the constant “fight” against their natural tendencies “takes much effort and energy” (McKean, 1994, p. 39) and can result in an extreme level of tiredness: “Deep down inside me, I sometimes get so tired—you have such complicated rules in your world! And all the time I have to think and think and think about them” (Gerland, 1997, p. 255). For Dominique Dumortier (2004), the task of effortful adaptation is so energy demanding that she cannot always keep it up:
Despite all my efforts I simply cannot prevent all autistic incidents. It’s a shame that it demands so much energy and exhausts me so much that I can never keep it up for long although I always try my best. (p. 93)

Although Dawn Prince-Hughes (2004) is “so successful at appearing normal (whatever that is),” that people are surprised when she reveals her diagnosis, she “also wish[es] at times people knew how hard [she] work[s] at it. So much goes on that other people can’t see” (p. 2). Dave Spicer (1998a, 1998b) wrote about this at some length. He said:

> It is possible, with a great deal of ongoing effort, for an autistic person to appear to be pretty much ‘like everyone else’ in some settings, at least. What is not visible from the outside is the amount of work—and stress—involved in maintaining this facade. (1998a)

Dave Spicer (1998b) explains not only how difficult a conscious effort to “appear” “like everyone else” is, but also how, despite his best effort, its results never match the effort:

> It was like trying to build a house on swampy ground which could not support any weight despite looking all right at first glance, or like trying to ice skate on a pond which in many spots was barely frozen over. In each of these cases, the surface impression does not at all reflect what lies beneath, or the fragility of what is seen. (p. 379)

Donna Williams (1998) wrote about the effects of “acting normal” on her feelings about herself and the world, and on her identity:

> But it wasn’t that simple. Here was a world which was showing me that everything I identified with was worth nothing. . . . This angered me, it pained me, it alienated me and it confused me. . . . It put my real self into what felt like exile. (p. 89)

Like their parents, autistic individuals also emphasize two sides of autism: one of ability, competence, and uniqueness (“the beautiful side of autism”; D. Williams, 1994, p. 115) and the other of incompetence and “disability.” For example, Dawn Prince-Hughes (2004) wrote, “Autism can be a beautiful way of seeing the world” (p. 2). Jerry Newport (2001) put his view as follows: “Technically, it [autism] is called a disability, but I have always thought of myself as ‘differently-abled’” (ix): “I am able and incompetent in a skewed, very different way. But I am not disabled” (p. 169). Gunilla Gerland (2002) described a full range of both positive and negative dimensions of autism (including its emotional consequences):
To me it means sadness (for causing me so many misunderstandings) and protection (from not having to understand peoples [sic] evilness) and it means satisfaction (because I don’t have a problem with spending a lot of time in my own company), and isolation (because I don’t know how to get close to people when I want), and disappointmen [sic] (in the NT [neurotypical—term used by autistic individuals to refer to non-autistic individuals] world not wanting to do even a small effort to understand me) and it means joy (from having an amazing sharpness of my eyes that makes me enjoy just looking at things) and it means intelligence (with the ability to not have a lot of feelings interfering with my thoughts) and it means beeing [sic] really good at a lot of things (since the thought of asking someone for help never occurred [sic] to me until lately) and freedom (from a lot of the IMO [in my opinion] strange things people seem to think is important).

It also has meant depression (growing up and not understanding what was wrong with me) but it doesn’t anymore. Autism is very contradictory to me, someone else wrote: ‘I’ve gained as much as I’ve lost’ and that goes for me too (maybe I’ve lost some more than I gained but that wasn’t because of the autism itself, but the lack of understanding from the world around me).

Autism probably means more to me than this, but this is what came to my mind right now.


In her autobiographical book entitled The Martian in the playground, Clare Sainsbury (2000), described how her feelings of confusion, fear, being different, and not fitting made her dream about going “home” from the world to which she came by mistake. Her description is so vivid that it deserves to be quoted in full:
Here is one of my most vivid memories of school: I am standing in a corner of the playground as usual, as far away as possible from people who might bump into me or shout, gazing into the sky and absorbed in my own thoughts. I am eight or nine years old and have begun to realize that I am different in some nameless but all-pervasive way.

I don’t understand the children around me. They frighten and confuse me. They don’t want to talk about things that are interesting. I used to think that they were silly, but now I am beginning to understand that I am the one who is all wrong. I try so hard to do what I am told, but just when I think I am being most helpful and good, the teachers tell me off and I don’t know why. It’s as if everybody is playing some complicated game and I am the only one who hasn’t been told the rules. But no-one will admit that it’s a game or that there are rules, let alone explain them to me. Maybe it’s all a joke being played on me; I know about “jokes”. I would be happy if they left me alone to think my thoughts, but they won’t.

I think that I might be an alien who has been put on this planet by mistake; I hope that this is so, because this means that there might be other people out there in the universe like me. I dream that one day a spaceship will fall from the sky onto the tarmac in front of me, and the people who step out of the spaceship will tell me, “It’s all been a dreadful mistake. You were never meant to be here. We are your people and now we’ve come to take you home.” (pp. 8–9)

The feeling of alienation is also highlighted by titles of several websites of autistic individuals such as Janet Norman-Bain’s homepage “Ooops . . . Wrong Planet! Syndrome” (1995–2005) and Alex Plank’s self-advocacy site “Wrong Planet” (2004–2009). In order to convey their feeling of not belonging, autistic individuals also use the notion of “living as a minority on Earth” (Newport, 2001, p. 12) or as “‘foreigners’ in any society” (Sinclair, 1993), or having a different, separate culture (Dekker, 1999; Grandin & Barron, 2005; Prince-Hughes, 2002; Sinclair, 1992, 1993, 2005). Temple Grandin and Sean Barron (2005) expressed this view as follows:

Autism is a spectrum disorder, and people with autism are a diverse culture. As with any culture, we have social norms, unwritten rules and a thought perspective all our own. That people with autism have to exist within a different culture on a day-to-day basis in order to survive—one that often blindly insists on conformity rather than respecting our cultural diversity—makes functioning in the world around us exceedingly difficult, often depressing and continually anxiety-laden. (p. xvi)

Finally, arguing against professionals’ views of autism as abnormality and of themselves as damaged or undeveloped people, Jim Sinclair (1993) suggested that autism is a different (not deviant) “way of being,” while Donna Williams (1998) put forth the idea that autism is not qualitatively (as postulated by the traditional psychiatric perspective)—but only quantitatively—different from a “normal” human condition:
“Autism” is simply an internal human “normality” with the volume turned up [emphases added]. . . . For me, the experience of ‘autism’ is . . . the frequency and extremity with which [things] are experienced and the degree to which these experiences affect how one expresses oneself and relates to one’s inner world and the outer world. It’s a matter of whether you visit these states or whether you’ve lived there. (pp. 9–10)

Donna Williams (1996a) also argued against professional value-laden descriptions of autism and for a more respectful view, one that appreciates diverse kinds of development and adaptation:

Those seeking to test people with ‘autism’ might begin by daring to imagine that these people may not be lesser-developed versions of non-autistic people [emphasis added] but, rather, people who HAVE developed, sometimes substantially, along a very different track from non-autistic people. Looking at how “autistic” people measure up to non-autistic people according to a non-autistic developmental path tells the researcher nothing about how far the same person may have developed a whole range of adaptations, compensations and strategies along an “autistic” track. (p. 235)

The argument that they are different—not deviant—culminated in autistic individuals’ claim that the efforts to find a “cure for autism” are misguided: they do not need to be cured, they need to be accepted (e.g., Holliday Willey, 1999; Sinclair, 1992). For example, Holliday Willey (1999) concluded her book Pretending to be normal as follows:

No matter what the hardships, I do not wish for a cure to Asperger’s Syndrome. What I wish for, is for a cure for the common ill that pervades too many lives; the ill that makes people compare themselves to a normal that is measured in terms of perfect and absolute standards, most of which are impossible for anyone to reach. (p. 121)

Michelle Dawson (2005), in her brief to the Senate Standing Committee on Social Affairs, Science, and Technology, which argued against the behavioral treatments for autistic children, suggested that

The premise of these comprehensive interventions . . . is that autistics inherently lack humanity and personhood. As human beings, we are write-offs. Autistic abilities and traits are assumed to be non-existent, or destructive, useless and wrong. There is everything to gain, and nothing to lose, if our lives are dedicated to striving every minute to be normal, that is non-autistic. The goal of this kind of intervention, Ivar Lovaas has repeatedly written, is to build a person where none exists.
However, it is Jim Sinclair (1992) who should be credited with the first public protest in academic literature against experts’ degrading and dehumanizing views on, and treatments for, autistic individuals. In his now-famous essay *Bridging the gaps: An inside-out view of autism (Or, do you know what I don’t know?)*, published in an established series of edited books on autism by Schopler and Mesibov, Jim Sinclair wrote,

> What is normal for other people is not normal for me, and what is normal for me is not normal for other people. . . . But my personhood is intact. My selfhood is undamaged. I find great value and meaning in my life, and have no wish to be cured of being myself. . . . Grant me the dignity of meeting me on my own terms—recognize that we are equally alien to each other, that my **ways of being are not merely damaged versions** [italics added] of yours. (p. 302)

In fact, Jim Sinclair’s views (1992) represent the beginning of a whole social movement—known as “neurodiversity” (Harmon, 2004; J. Singer, 1999) or “autism rights movement” (A. Solomon, 2008)—that fights for social acceptance of autism as a different way of being, or a neurological difference, rather than a mental disorder or disability. This movement was facilitated by the opportunities provided to autistic adults to present their “first-person perspective” on autism at professional conferences where they began discussing autism-related issues among themselves (Sinclair, 2005). As a result of this exchange, they started to form self-advocacy groups (e.g., Autism Network International—ANI), publish their own newsletters (e.g., “Our Voice”), operate e-mail and online discussion forums (e.g., ANI-L), hold their own conferences (e.g., Autreat, 1996–2008; Sinclair, 2005), and publish their views on self-advocacy sites and/or personal home pages (e.g., *Autism Network International*, ANI, 1992–2009; *No autistics allowed: Explorations in discrimination against autistics*, Dawson, 2003–2008; *Ooops... Wrong Planet!*, Norman-Bain, 1995–2004).

Although the movement started with the idea that there was nothing wrong with being autistic, as Jim Sinclair initially claimed, it soon changed its tone when Temple Grandin expressed the idea that it was even desirable to be autistic. She said, “If I could snap my fingers and be non-autistic, I would not, because then I wouldn’t be me. Autism is part of who I am” (Sacks, 1995, p. 278). Temple believes that her good visual abilities, which allowed her to become a successful livestock equipment designer, are part of autism; hence, she wrote, “I would never want to become so normal that I would lose these [visual] skills” (Grandin, 1995c, p. 180). Temple even
went one step further, and after gathering some evidence from biographical sources, claimed that some well-known figures from the history of arts, science, and technology such as Albert Einstein, Ludwig Wittgenstein, Vincent van Gogh, and Bill Gates had “autistic traits” (Grandin, 1992, 1995b, 1995c).

Soon many other autistic individuals started to express their pride in being autistic in their autobiographies (e.g., Holliday Willey, 1999; O’Neill, 1999; D. Williams, 1996a) and/or the Internet (e.g., ANI, 1992–2009; Norman-Bain, 1995–2004). Today, it is quite common among high-functioning autistic individuals (both adolescents and adults) to refer to their autistic features as gifts (e.g., L. Jackson, 2002; Mór, 2007; O’Neill, 1999). For example, 13-year-old Luke Jackson (2002) wrote, “One unusual thing about me is that I have what some people would call a disability but I call a gift—Asperger Syndrome (AS)” (p. 19). Similarly, Caiseal Mór (2007), a well-known autistic fiction writer, elaborated his view in his autobiography A blessing and a curse:

In my humble opinion autism is a wondrous gift—a blessing of sorts. As far as I’m concerned, autistic benefits far outstrip any drawbacks you can imagine. But it’s taken me a lifetime of self-examination and inquiry to arrive at that conclusion. (p. 9)

A final point of many, although not all, autistic individuals’ contentions with experts on autism concerns the very labeling of themselves as people “with autism” (e.g., Dekker, 1999; Sinclair, 1999; Schwarz, 2004; see also Harmon, 2004). These individuals’ view is best expressed by Jim Sinclair (1999), in his essay Why I dislike “person first” language, in which he stated, “I am not a ‘person with autism.’ I am an autistic person” and gave the following reasons for it: First, unlike a shirt he wears, autism is part of him, and it cannot be separated from him, which the expression “person with autism,” like the expression “person with a blue shirt,” suggests. Second, the expression “person with autism” suggests that autism is not a very important characteristic of that person because characteristics that are central to people’s identities—as autism is—such as male, Catholic, generous, or outgoing, are normally stated as adjectives, not as nouns: “people with maleness,” “femaleness,” Catholicism and so on. Third, the expression “person with autism” “suggests that autism is something bad—so bad that [it] isn’t even consistent with being a person.” Referring to the origins of the idea of the “person first” language, he concluded,
It is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person. I know that autism is not a terrible thing, and that it does not make me any less a person. If other people have trouble remembering that autism doesn’t make me any less a person, then that’s their problem, not mine. Let them find a way to remind themselves that I’m a person, without trying to define an essential feature of my personhood as something bad. I am autistic because I accept and value myself the way I am.

Out of respect for autistic individuals’ stated preference, and following their usage of the term in most of the reviewed autobiographies, I refer to “autistic people,” and not to “people with autism” which is preferred among experts. As Michelle Dawson expressed in an email to a journalist, “I would appreciate it, if I end up in your article, if you describe me as ‘an autistic’ or ‘an autistic person’, versus the ‘person with . . .’.” (as quoted in Harmon, 2004).

Before concluding this review, it is important to emphasize that a lot of information obtained from a first-person perspective on autism has found its way into mainstream science by inspiring research on, for example, autistic intelligence (M. Dawson et al., 2007), sensory processing (S. J. Rogers & Ozonoff, 2005), and the distribution of autistic traits in the general population (Skuse, Mandy, & Scourfield, 2005). Moreover, many autistic individuals’ views, initially contradicting those of experts, have been supported by recent research evidence. For example, the idea of autism as a quantitative, not qualitative, difference has been empirically supported by recent genetic studies (e.g., Constantino & Todd, 2003; Ronald et al., 2006; Skuse et al., 2005; Spiker, Lotspeich, Dimiceli, Myers, & Risch, 2002).

However, it is also important not to forget that ideas similar to those of autistic individuals were also expressed by Asperger (1944/1991, 1979). For example, as already mentioned, discussing “the social value” (p. 87) of “autistic intelligence,” Asperger expressed a very similar view to that of today’s autistic advocates. Moreover, Asperger’s original term for what is now known as Asperger syndrome was “autistic psychopathy,” which was closer in its meaning to the extreme of the normal personality than to the pathology (R. Blackburn, 1998). In fact, Asperger (1944/1991) used the term “autistic psychopathy” interchangeably with “autistic personality” (e.g., pp. 58, 67, 84, 87) and remarked that his view of psychopathy was “consistent with Schröder’s view of personality disorder or psychopathy; [who] maintained that psychopaths are
not mad, nor half nor quarter mad” (p. 87). Unfortunately, the rest of his seven-page discussion about then-contemporary views on psychopathy was not translated. However, interpretations of several authors who read Asperger’s original paper suggest a view of autistic psychopathy very similar to that of autistic individuals’ view of autism. For example, Lyons and Fitzgerald (2005) suggested that “Asperger believed that ‘autistic psychopathy’ . . . overlapped with the ‘normal continuum’” (p. 39). Likewise, Van Krevelen (1971) took autistic psychopathy to mean a “personality trait” as opposed to Kanner’s autism, which was a “psychotic process” (p. 84)—which is a view close to Jaspers’ (1923/1963) view of psychopathy. (In his classic text of that time, General psychopathology, Jaspers used the term psychopathy to refer to a “variation of human life,” [p. 789] substantially different from psychoses, or mental illnesses.)

Importantly, and consistent with Asperger’s intentions, in her introduction to Asperger’s paper (which she translated and published), Frith (1991), asked:

Does it make sense to talk about deficits and exclusive categories? Should one instead talk about normal and abnormal behaviour shading into each other? To put it another way, should one look at Asperger Syndrome as a normal personality variant [italics added]? (p. 23)

However, even despite the previously-mentioned attempts of Frith and her colleagues to account for autism’s strengths and weaknesses in their empirical and theoretical work, in which they suggested that autistic individuals have a different cognitive style rather than a deficit (Frith & Happé, 1994; Happé, 1999), these questions were largely ignored for almost a decade. In fact, the inclusion of Asperger syndrome as a new diagnostic category in the manual of mental disorders (DSM-IV; APA) in 1994 represents a clearly negative answer by the scientific community to Frith’s question: the manual changed the name Asperger syndrome to Asperger’s Disorder and defined it exclusively in terms of “impairments.”

Although some clinicians (e.g., Attwood, 1998; Sacks, 1995) continued to paint a more balanced view of individuals with Asperger syndrome by emphasizing their strengths and reminding us that “great advances in science and art have been attributed to people with Asperger syndrome” (Attwood, 1998, p. 127), the first positive academic answers to Frith’s questions appeared only in 2000. They came from Baron-Cohen, who in an article entitled “Is Asperger syndrome/high-
functioning autism necessarily a disability?” (2000a) explicitly addressed Frith’s last question (as well as Jim Sinclair’s invitation to fairness). He concluded that the “term ‘difference’ in relation to AS/HFA [Asperger syndrome/high-functioning autism] is a more neutral, value-free, and fairer description than terms such as ‘impairment,’ ‘deficiency,’ or ‘disability’” (p. 489). (Also relevant is Baron-Cohen, Wheelwright, Stone, and Rutherford’s (1999) article entitled “A mathematician, a physicist and a computer scientist with Asperger syndrome: Performance on folk psychology and folk physics tests.”)

In recent years, an ever-increasing number of empirical studies have focused on positive aspects of autism (e.g., Järvinen-Pasley, Wallace, Ramus, Happé, & Heaton, 2008; M. Dawson et al., 2007; O’Riordan & Plaisted, 2001; O’Riordan, Plaisted, Driver & Baron-Cohen, 2001; Plaisted, O’Riordan, & Baron-Cohen, 1998). In addition, a number of retrospective psychobiographical analyses of the lives of historical figures suggested to have been autistic have also been published (Fitzgerald, 2002, 2004, 2005; Lyons & Fitzgerald, 2005). Consistent with Temple Grandin’s intuitions about Einstein, van Gogh, and Wittgenstein, these studies identified many other famous people who might have met the current criteria for a diagnosis of Asperger syndrome. They include musicians Ludwig Van Beethoven, Glenn Gould, and Wolfgang Amadeus Mozart; writers Lewis Carroll, Arthur Conan Doyle, Herman Melville, and George Orwell; philosophers Spinoza, Immanuel Kant, and Ludwig Wittgenstein; painters and visual artists Vincent van Gogh and Andy Warhol; film director Stanley Kubrick; scientists Charles Darwin and Albert Einstein; and mathematicians Paul Erdos, Gauss, G. H. Hardy, and Ramanujan. Consequently, as already mentioned, theorizing on autism has also become more balanced, which is best illustrated in Baron-Cohen’s (2003) reformulation of his “mindblindness” hypothesis (1995), which had no room for positive aspects of autism, into the empathizing-systemizing thesis, which takes into account both weaknesses and strengths of autistic individuals.

1.4.1 Summary and New Directions

Autistic individuals present a unique first-person perspective on autism as a human condition that challenges the psychiatric perspective that considers autism a disease and abnormality,
offering a more neutral view of autism as a human variation. According to this view, autism is the difference in quantity (or, as Donna Williams put it, in the “volume”; 1998, p. 9) of autistic features rather than in quality. The first-person perspective also challenges the narrow psychological views of the core deficits established with reference to “normal” development and instead suggests unique developmental paths (a view also recently adopted by some scholars; e.g., Karmiloff-Smith, 1998). Furthermore, this perspective offers a unique glimpse into the multidimensionality of autistic individuals as persons with unique skills and personalities that goes beyond psychiatric “core symptoms” and psychological “core deficits”—a point well summed up by Temple Grandin (Grandin & Barron, 2005): “While people with ASDs [autism spectrum disorders] are similar in many ways, we each bring to the equation a unique personality that contributes as much to our development as do the characteristics of autism we manifest” (p. 53). Finally, the first-person perspective offers a unique perspective on what it feels to be autistic and suggests a deep feeling of alienation that resembles living in another world.

Although many insights from autistic individuals have found their way into the science on autism, suggesting a shift towards a more comprehensive approach, two very important aspects of autism, the subjective experiences and the meaning making of these experiences by autistic individuals, have not yet been adequately addressed in research. In fact, only a few studies have explored aspects of subjective experiences of autistic individuals to any extent (e.g., Cesaroni & Garber, 1991; Hurlbutt & Chalmers, 2002, 2004; Molloy & Vasil, 2002), so that only very limited information about this important issue is currently available. Therefore, an important aim of this study is to contribute to this small body of evidence.

2 Life Outcome for Autistic Individuals

As reviewed above, until recently, the main focus of autism research has been on understanding the nature of autism—that is, its causes and core symptoms and deficits—and relatively little is known scientifically about the real life experiences of autistic individuals. Further, most research on autism has been done with autistic children, and not much is known about the life course of autistic individuals or about autism in adulthood (Howlin, 2007). Indeed, until relatively recently, autism was considered a childhood disorder (Grinker, 2007; Wing, 1998), and it was
often assumed (despite evidence to the contrary) that autistic children become adults with schizophrenia (Grinker, 2007).

In this section, I briefly review what is known about the long-term life outcomes for autistic individuals from clinical and empirical studies, and from autobiographical accounts.

2.1 Clinical Reports

The first observations of adult outcomes for autistic individuals were made by Asperger (1944/1991). As already mentioned, he noticed that the outcomes were highly variable and concluded that, while the majority did not make good progress, a minority of autistic individuals—those with good intellectual abilities—do well in later life. Moreover, he suggested that this minority can make significant contributions to society, describing their achievements as “exceptional” (p. 37) and “outstanding” (p. 88). He wrote,

To our own amazement, we have seen that autistic individuals, as long as they are intellectually intact, can almost always achieve professional success, usually in highly specialized academic professions, often in very high positions, with a preference for abstract content. We found a large number of people whose mathematical ability determines their professions; mathematicians, technologists, industrial chemists and high-ranking civil servants. (p. 89)

Asperger attributed autistic individuals’ success to their “penetrating intellectual powers,” their “unswerving determination,” and the “narrowness and single-mindedness” (p. 88) of their interests. He also firmly believed in the value of specialized educational treatments for autistic children.

For his part, Kanner (1971) published a twenty-eight-year’s follow-up study of the 11 children whom he had initially observed in 1943, in which he further described the life course of nine of these children whom he was able to contact again. Like Asperger, he also found that the outcomes were extremely variable, “ranging all the way from complete deterioration to a combination of occupational adequacy with limited, though superficially smooth social adjustment” (p. 144). Although Kanner estimated that the nine children had been initially similar
in their basic symptoms, he described only two of them as having achieved good outcomes in adulthood. The best outcomes, described by Kanner as “real success stories” (p. 143), were achieved by 36-year-old Donald T. and 34-year-old Frederick W. Both men held regular jobs (Donald as a bank teller; Frederick as a duplicating machine operator) and were well integrated into their social environments. For example, Kanner wrote that Donald “takes part in a variety of community activities and has the respect of his fellow townspeople” (p. 144). Kanner also noted that people who knew Donald and Frederick well described them in positive terms. For example, Donald was described by his mother as “dependable, accurate . . . even-tempered but [with] a mind of his own” (p. 121), while Frederick was described by his firm’s director as “an outstanding employee by any standard,” that is, in terms of “dependability, reliability, thoroughness, and thoughtfulness toward fellow workers” (p. 124). Both men lived with their parents and did not have any close relationships. Donald was also described by his mother as not having any interest in the opposite sex.

In his effort to explain the wide discrepancy in outcomes, Kanner (1971) wrote that not being institutionalized was associated with a better outcome. He also wondered “whether another element, not as yet determinable” may have contributed to the two good outcomes. Although he did not speculate as to what that element might be, his comment about “the intuitive wisdom” (p. 143) of people who cared for Donald could be taken as an implicit recognition of its potential contribution: he described several ways in which they made Donald’s stereotyped preoccupations meaningful by finding “goals” for them (p. 121). He wrote that they “knew how to make [Donald] utilize his futile preoccupations for practical purposes” (p. 143).

In 1972, Kanner and his colleagues described the life course of nine other individuals, ranging in age from 22 to 35 years—selected from a group of 85 autistic individuals—considered to be “functioning in society” (p. 27). This study further confirmed Kanner’s initial observation that outcomes for autistic individuals are highly variable. According to Kanner and his colleagues, these nine individuals had made good social adjustments or, as they put it, were “sufficiently integrated into the texture of society to be employable, move among people without obvious behavior problems, and be acceptable to those around them at home, at work, and in other modes of interaction” (p. 10). Of these nine individuals, one was a university student, and eight held
jobs as a restaurant dishwasher and bus boy, a “blue collar” worker, a helper in a drug store, a page in a library, a file clerk, a truck loading supervisor, a lab technician, and an accountant. Educational attainments of these individuals ranged from university and college degrees (including one Masters degree in Economics and one BA degree in History) to vocational training in a sheltered workshop (one individual). A high level of education, however, did not necessarily translate into a better job. Thus, the individual who obtained a BA degree in history worked as a “blue collar” worker. Most of these individuals lived independently in their apartments, or owned homes; several belonged to social groups or clubs (such as singing, hiking, swimming, and streetcar museum groups); and several either were or had been in dating relationships. However, there was no evidence of close or intimate relationships, and not one was married.

Kanner and his colleagues (1972) considered several factors that could have contributed to good life outcomes. They concluded that, although several factors seemed to be important, including acquiring communicative language before the age of 5 years and not being institutionalized, these factors were not specific to the group that made the best adjustment. Instead, what seemed specific to this group were gradual increases in self-awareness and a “conscious effort” to change “along the road to social adaptation” starting in adolescence (p. 29). They wrote that, before adolescence, autistic children did not differ from one another in “a form of existence which was had, lived, experienced rather than contemplated or reacted to” (p. 29). However, they wrote, “a remarkable change took place” in the early to middle adolescence (p. 29):

Unlike most other autistic children, they became uneasily aware of their peculiarities and began to make a conscious effort to do something about them. This effort increased as they grew older. They “knew,” for instance, that youngsters were expected to have friends. Realizing their inability to form a genuine buddy-buddy relationship, they—one is almost tempted to say, ingeniously—made use of the gains made by their obsessive preoccupations to open a door for contact. (pp. 29–30)

Kanner and his colleagues (1972) emphasized that autistic individuals who made the best social adjustment (estimated at 11 to 12% from combined 1971 and 1972 studies) did so “without any specific intervention” (p. 32), and wondered whether interventions might increase this ratio in the future. In fact, a year earlier, Kanner (1971) was optimistic that results of follow-up studies of other groups of autistic children over the next 20 or 30 years would provide grounds “for a
more hopeful prognosis” (p. 145) than the results of his follow-up of 11 children which found a successful outcome in 18% of cases (i.e., 2 out of 11).

Unfortunately, this optimistic outlook did not materialize 20 years later, when Tantam (1991) published the results of his study which focused specifically on the longer term outcomes of adults with Asperger syndrome. In this study of 46 British adults with Asperger syndrome (5 of whom had IQs below 70; mean age 24 years), only 4 (9%) individuals were employed, 1 (2%) was married, and 1 lived independently (the rest either lived with their parents or were in residential care). (It should be noted that only 37 out of 46 [80%] individuals in this study were questioned about independence.) Tantam noted that relatives credited the improvement in autistic individuals “to active socialization, with limits on time spent in withdrawal into special interests, inactivity or stereotypy,” as well as to “their own efforts, encouragement from younger siblings and particular schools” (p. 179).

In summary, clinical observations provided significant insights about long-term outcomes of autistic individuals, suggesting the importance of several factors that include both the individual’s own efforts as well as social support. Next, I review results of empirical outcome studies.

### 2.2 Long-Term Empirical Outcome Studies

Only a small corpus of long-term outcome studies of autistic individuals is available (for a recent review, see Howlin, 2007). The majority of these studies involved heterogeneous samples that included both high- and low-functioning autistic individuals, and most participants were relatively young (many still in school), so that only limited information about longer-term outcomes of high-functioning autistic adults is available.

Six of the earliest long-term follow-up outcome studies of autistic adults who were predominantly high-functioning (age range, 17–44 years; sample size range, 9–43) were comprehensively reviewed by Howlin (2000c). The review includes five published studies (Larsen & Mouridsen, 1997; Mawhood, Howlin, & Rutter, 2000; Rumsey, Rapoport, & Sceery,
1985; Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989; Venter, Lord, & Schopler, 1992) as well as one study referred to as “in preparation” at the time (Good, Howlin, & Rutter); however, this latter study could not be identified during literature search of subsequently published studies although Howlin and her colleagues’ (2004) study is partly based on the same data. In her review, Howlin (2000c) found that the outcomes—rated based on composite scores obtained from information about education, level of independence, employment status, and social relationships—were extremely variable. For example, the proportion of individuals who achieved a “good” outcome ranged from 16% (Mawhood et al., 2000) to 44% (Rumsey et al., 1985). Likewise, the ratio of individuals who were regularly employed ranged from 5% (Mawhood et al., 2000) to 55% (Venter et al., 1992), and the ratio of individuals who lived independently ranged from 16% (Mawhood et al., 2000) to 50% (Larsen & Mouridsen, 1997). However, one finding was consistent across studies: the proportion of individuals who had any close social relationships was very small and only 0 to 2% were married. Factors found to be related to outcome included cognitive and linguistic abilities, the level of local support (such as the availability of appropriate educational and supported employment programs, and social skills groups), and an early diagnosis (necessary to provide local support).

Three outcome studies that focused on or reported separate data about high-functioning individuals were published after Howlin’s review (2000c). The first study was the UK National Autistic Society’s cross-sectional mail survey of 450 parents of autistic adults, 217 of whom were high-functioning (Barnard et al., 2001). According to this study, only 12% of high-functioning autistic adults (no age range was provided) were in full-time paid employment, and a further 6% were employed part-time. A quarter (24%) were described as “doing nothing at all or ‘helping out around the house’” (p. 7). Only 3% were living fully independently, and a further 8% were living independently with regular professional or family support. Fifty-nine percent were living at home with their parents. Thirty-seven percent had no social activities at all.

In a second Swedish study of 16 high-functioning autistic individuals (age range 23–46 years), also cross-sectional, Engström and his colleagues (2003) found that 2 individuals (12%) achieved good outcomes (defined as “normal or near normal social life and satisfactory functioning at school or work,” p. 103). The same proportion (2 individuals, or 12%) achieved poor outcomes, defined as a severe handicap with no independent progress. Only one individual
was regularly employed, while several worked under special arrangements such as in sheltered employment settings or employment provided by relatives. Thirteen (81%) received disability benefits from the government. Although 9 (53%) owned homes, only one was able to live with minimal extra support. Not one was married or had children, and only a few had close relationships. The finding that most lived in their own homes deserves special consideration. This finding is in contrast to previous findings from the UK (Mawhood et al., 2000) and North America (Rumsey et al., 1985; Szatmari, Bartolucci, Bremner, Bond, et al., 1989; Venter et al., 1992) but in accordance with findings from Denmark (Larsen & Mouridsen, 1997). The authors explained this pattern by referring to the Scandinavian governments’ polices toward disabled people, which promote independent living. For this reason, the authors did not view living independently as a valid index of psychosocial functioning and highlighted the fact that almost all individuals needed extensive support from their families and/or society.

The third study (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008), also from Sweden, is the first long-term follow-up study of a larger group of individuals with Asperger syndrome (n = 70; age range, 16–34 years; average IQ = 103, range, 66–143⁹). However, individuals with Asperger syndrome represent only half of the sample in this study, and the other half were low-functioning autistic individuals, in which only five (7%) individuals had intellectual ability in the normal range at follow-up, and none had good outcome. In this study, 19 individuals (27%) achieved a good outcome, while a similar proportion (26%) achieved a “restricted” and “poor” outcome. “Good outcome” in this study was defined as (a) having a job or being in age- and IQ-appropriate education or vocational training, and (b) living independently, if older than 23 years, or having two or more friends or a steady relationship, if 22 years or younger. “Poor outcome” was defined as “obvious severe handicap, with either of, no independent social progress or presence of a major psychiatric disorder, but with some clear verbal or non-verbal communicative skills” (p. 122). “Restricted outcome” was defined in the same way as poor outcome except that people in this category are better accepted by peers or personnel, which makes their handicaps less obvious. Seven individuals (10%) held regular jobs and a further 6 (9%) were involved in occupational activities in a group centre, while 12 (17%) had no

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⁹ IQ above 70 is considered to be in the normal range. Only one individual in this group had IQ below 70; two individuals’ IQs were above 130.
organized daily activity at all and depended on social assistance from the government. Of those aged 23 years and older, 14 (64%) lived independently (i.e., away from their parents); however, they all depended on their parents for support. Three individuals lived in a long-term relationship, and a further 10 had had relationships in the past. In general, given the intellectual level of the group and the outcome criteria used, the authors concluded that the group’s outcome was worse than expected. Although at first glance this outcome seems much better than that of Engström and his colleagues (2003), it should be noted that the majority of this sample (48 participants, or 69%) was still relatively young (16–22 years) compared to Engström and colleagues’ study participants, whose ages ranged from 23 to 46. Although Cederlund and colleagues did not report the outcomes for younger and older participants separately, they noted that “those with better outcomes had not been followed up for as long as those with restricted outcome” (p. 81), and the mean age of those with “good” outcome was 21.5 (SD 3.7) while the mean age of those with “restricted” outcome was 23.5 (SD 4.8). The fact that only 10% were in regular employment also supports the idea that the differences in outcome between the two studies may, at least in part, be related to the age differences of the two samples. Cederlund and colleagues identified three factors as potentially relevant to good outcome: higher intellectual abilities, younger age at diagnosis, and the absence of psychotic disorders. However, the associations of these with outcomes were reported as only statistically non-significant trends.

Finally, although not focusing specifically on high-functioning autistic individuals, a longitudinal UK study by Howlin and her colleagues (2004) deserves special consideration because of its investigation of factors that might predict outcomes for autistic adults based on their childhood characteristics, as well as serving as a comparison study for Kanner and colleagues’ (1972) study. Sixty-eight autistic individuals (age range, 21 to 49; mean non-verbal IQ on the WISC = 80.21, SD = 19.28, range 51–137) participated in this study, but although most participants were high functioning (45 individuals [66%] obtained childhood performance IQs between 70 and 137 and 10 [15%] had IQs ≥ 100), the outcomes of the high-functioning subgroup was not reported separately. However, it seems they were already reviewed by Howlin (2000c). In this study, 8 individuals (12% of the whole group) achieved a “very good” outcome, defined as having paid employment, some friends and a high level of independence. An additional 7 individuals (10%) had a “good” outcome, defined as working but requiring some support, having some friends, traveling independently, and organizing their own activities. More than half of the group (39
individuals, or 58%) were rated as having a “poor” or “very poor” outcome: 31 individuals, or 46%, had a “poor” outcome, defined as living in residential accommodation or at home with very limited autonomy; and a further 8, or 12%, had a “very poor” outcome, defined as living in long-stay hospitals. Thirteen individuals (19%) had a “fair outcome” defended as living at home and requiring considerable support in daily living but having some degree of autonomy. At the level of the whole sample, a better childhood IQ predicted a better outcome; however, individuals with childhood IQs over 100 did not have better outcomes in adulthood than individuals with childhood IQs between 70 and 99.

One cannot help but notice that the proportion of individuals rated as having a “very good” outcome (approximately 12%) in Howlin and colleagues’ (2004) study is almost the same as that in Kanner and colleagues’ (1972) study conducted some 30 years earlier. Although it is extremely difficult to make direct comparisons between outcome studies conducted across historical, geographical, and political contexts, some parallels can still be drawn. Both studies used clinical samples from large cities (London and Baltimore, respectively) and broadly similar criteria for defining a “very good outcome” (i.e., full-time employment, a high level of independence, and social relationships). However, while Kanner and colleagues’ sample included all individuals diagnosed at their hospital (N = 98; diagnoses made from 1938 to 1953), Howlin and colleagues excluded individuals with IQs less than 50 from their sample (n = 68; diagnoses made from 1950 to 1979). Consequently, the ratio of “very good” outcome cases in Kanner and colleagues’ more impaired sample could be considered a “better outcome” than the ratio of “very good outcome” cases in Howlin and colleagues’ study. This tentative conclusion is particularly intriguing in light of the fact that an ever-increasing number of specialized interventions and services have been made available to autistic individuals over the intervening 30 years.

Furthermore, findings from other reviewed studies seem to support the above conclusion: the same proportion—around 12%—of good outcome cases were reported in two recent cross-sectional studies conducted with only high-functioning autistic individuals (Engström et al., 2003). Thus, although 12% of the participants in Barnard and colleagues’ study (2001) had full-time employment, only 11% were living more or less independently (3% fully, and 8% with regular professional or family support). These findings must be taken as a much worse outcome
than a similar outcome for autistic individuals of all levels of abilities. Finally, although Cederlund and colleagues’ (2008) report of 27% of cases with good outcomes seems to contradict any suggestion of worsening outcomes over time, a closer examination of the age range age range (16–34 years; 69% were 16–22 years) of this study’s sample suggests that this outcome may not be representative of relatively older autistic individuals, and thus may not be directly comparable to outcomes reported in other studies (e.g., Engström et al., 2003; Howlin et al., 2004).

Still, although it is possible to argue that outcomes for high-functioning autistic adults are even worse today than 30 years ago, this remains a tentative conclusion (for a variety of reasons involved in the above comparisons). However, given the above findings and arguments, it seems safe to conclude that Asperger’s (1943) and Kanner’s (1971) optimism about improving long-term outcomes for autistic individuals has not yet materialized, as most high-functioning autistic adults still depend on support from their families and others, are not employed, have no close friends, and the ratio of those successfully integrated into society is no better than it was some 30 years ago. Howlin and colleagues (2004) came to the same conclusion: “On the whole, it would appear that the huge increase in educational facilities for children with autism over the past 3 decades has not necessarily resulted in significant improvements in outcome for adults” (p. 225).

Another conclusion concerns the factors that influence a good outcome for high-functioning individuals. In contrast to a consensus that having an IQ > 50 and communicative speech at 5 to 6 years of age are predictive of better outcomes for low-functioning individuals (Lord & Bailey, 2002; Nordin & Gillberg, 1998), neither a high IQ nor high level of language has been found to be predictive for the outcomes of high-functioning autistic individuals (Cederlund et al., 2008; Howlin et al., 2004; Lord & Bailey, 2002; Nordin & Gillberg, 1998). Unfortunately, the role of other factors—including self-awareness and deliberate change, suggested by Kanner and colleagues as early as 1972—have not yet been explored.

Finally, although being employed, living independently, and having social relationships are important social indicators of a successful life, their achievement may not necessarily lead to people’s feeling of having a “successful” life. In other words, a person who is judged by experts as having achieved a good life outcome based on the “objective criteria” may not feel satisfied
with one’s life, and vice versa. Therefore, as already suggested by Lord and Venter (1992) and argued by Ruble and Dalrymple (1996), an assessment of good life outcome of autistic individuals should ideally include some measure of the subjective evaluation of one’s life (subjective well-being). Next, I review an even smaller corpus of literature that explored subjective evaluations of life outcomes (life satisfaction) of high-functioning autistic adults.

2.3 Studies of Quality of Life of High-Functioning Autistic Adults

Although it has long been recognized that a high level of satisfaction with one’s life, or high subjective well-being, is a necessary, although not sufficient, feature of a good life (Diener, Oishi, & Lucas, 2003; Orley, Saxena, & Hermans, 1998), the inclusion of subjective evaluations in research on life outcomes is only a relatively recent practice. This practice is associated with a broader and more person-oriented perspective on the life outcome—the quality of life approach. The World Health Organization Quality of Life (WHOQOL) Group (1998a) defined quality of life as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (p. 551). Despite this emphasis on the subjective component, the quality of life perspective often includes both subjective and objective assessments (Oliver, Holloway, & Carson, 1995; Verdugo, Schalock, Keith, & Stancliffe, 2005).

Additionally, in contrast to traditional conceptions of life outcomes in literature on autism and other disabilities that included domains such as employment, independence, and social relationships, the quality of life perspective includes multiple domains typically encompassing several sub-domains. Although domains and their numbers vary across disciplines and investigators, they often include aspects such as physical well-being, emotional well-being, social well-being, material well-being, rights, living situation, family, recreation and leisure, and safety/security (Verdugo et al., 2005).

Although quality of life has been increasingly investigated in clinical and disability research (Hansson, 2006; Schalock et al., 2002), only two studies have explored the quality of life of high-functioning autistic adults.
In the first study, Jennes-Coussens, Magill-Evans, and Koning (2006) used a WHOQOL Group’s (1998b) questionnaire to compare the quality of life of 12 young Canadian high-functioning adults (all men, age range, 18–21; 25% students; 50% employed) to those of control subjects. The subjects rated the quality of their lives overall, as well as in health, social, psychological and environmental domains. Autistic subjects rated the overall quality of their lives lower than did control subjects. The overall quality of life was correlated with the social support network, which did not differ from that of control subjects. Autistic individuals were also less satisfied with their physical health and social relationships. Although the lower level of satisfaction in the social domain was expected, the authors considered the low satisfaction with physical health (that included aspects such as energy, fatigue, mobility, sleep, and rest) surprising. In the social domain, although the number of close friends in the two groups was very similar, half of the autistic individuals, compared to 15% of non-autistic subjects, had never dated and only two (17%) were dating at the time of the study, which probably contributed to the lower satisfaction with social relationships. There were no significant group differences in the psychological and environmental domains. Within environmental domain, it is interesting that the groups were similar in living arrangements (i.e., 75% of autistic and 61% of non-autistic individuals were living with family); however, given the young age of subjects, this similarity is not surprising. Autistic adults spent significantly more time in leisure activities, which is in accord with their lower employment rates (50%, half of which was part time; vs. 85% of non-autistic subjects, 18% of which was part time). Unfortunately, the authors did not elaborate on the finding of no difference in the psychological domain. Given that autistic individuals rated the overall quality of their lives lower than the non-autistic subjects and given the specific questions that comprise the psychological domain (e.g., How much do you enjoy life? To what extent do you feel your life to be meaningful? How satisfied are you with yourself? How often do you have negative feelings such as blue mood, despair, anxiety, and depression?; WHOQOL Group), there being no difference in the psychological domain seems surprising because it suggests that autistic individuals were as satisfied with their lives as the control subjects despite the lower quality of life ratings.

In the second study, Renty and Roeyers (2006) explored the predictive values of severity of autistic symptoms, IQ, and support characteristics for the quality of life of 58 Belgian autistic
adults (age range, 18–53; 29% students; 46% employed in mainstream or supported/sheltered employment). It is interesting that the employment rates reported in these two quality of life studies (Jennes-Coussens et al., 2006; Renty & Roeyers, 2006) seem higher than those reported in traditional life outcomes studies reviewed above. Nevertheless, Jennes-Coussens (2006) and her colleagues commented that, compared to adult males in the province (i.e., Alberta; 4.7% unemployment rate), the 50% unemployment rate for autistic participants was high, but that it was similar to that of people with a “moderate” disability. Somewhat surprisingly, these authors suggested that employment rates of autistic individuals in their study were similar to those of other studies reviewed above (e.g., Barnard et al., 2001; Engström et al., 2003; Howlin et al., 2004). Likewise, approximately half of the sample (46%) in the Renty and Roeyers’ (2006) study was employed: half in the mainstream employment, half in sheltered or supported employment or in a day activity program. Comparing these rates to earlier outcome studies, the authors noted that they were less positive than those of participants in several other studies (e.g., Szatmari, Bartolucci, Bremner, Bond, et al., 1989; Venter et al., 1992), but better than the rates reported by Mawhood et al. (2000) and suggested that these discrepancies could be due to possible differences in access to supported employment as well as differences in social, political, and economical factors.

Renty and Roeyers (2006) also found that higher quality of life—measured by an instrument that combines both subjective and objective ratings—was associated with higher perceived social support but not with the severity of autistic symptoms or IQ. However, as the authors recognized, the study’s design does not allow any conclusions regarding whether higher levels of perceived social support lead to higher levels of quality of life, or vice versa. Although the authors did not report an overall level of the quality of life of autistic adults in this study, they reported that those either employed or studying had significantly higher quality of life scores than those who were “unoccupied”, but that the quality of life did not differ across age, gender, education, living arrangements, or intimate relationships.

To conclude, there is very limited information about high-functioning autistic individuals’ quality of life. The available information suggests a lower level of overall quality of life, as well as in the social and physical domains, and its association with perceived social support. However, information about autistic individuals’ satisfactions and dissatisfactions with a
multitude of life domains is still lacking. The only currently available sources for such information are autobiographical accounts of autistic adults, to which I turn next.

2.4 Autobiographies of Autistic Adults

Note. In this section, and in the remainder of the study (unless otherwise specified), I use the term autistic individuals to refer to high-functioning autistic individuals or individuals with Asperger syndrome.

An important source of information about the life outcomes of autistic adults is their published autobiographical writings (e.g., Barron & Baron, 1992; Gerland, 1997; Grandin & Barron, 2005; Grandin & Scariano, 1986; Dumortier, 2004; Holliday Willey, 1999, 2001; Prince-Hughes, 2004; D. Williams, 1992, 1994, 1996b, 2004a). These personal accounts clearly show that there is no one single path to a successful life outcome. Rather, each successful autistic person made the best use of available internal and external resources that included, among others, self-understanding, future orientation, perseverance, and social support. I briefly review evidence in support of this generalization.

Several autobiographers described having sudden self-insights which led to profound changes in their lives (e.g., Barron & Baron, 1992; Prince-Hughes, 2002, 2004; Grandin & Barron, 2005; Grandin & Scariano, 1986; D. Williams, 1994). For example, Dawn Prince-Hughes (2004) wrote about a dramatic change in her life after she discovered that she “could choose a course of action” (p. 91) as opposed to letting things happen to her. This realization contributed to changing her life from being a homeless high-school dropout to becoming a university professor. Similarly, Temple Grandin (Grandin & Scariano, 1986) reflected upon her adolescent discovery of the “freedom of choice [and] authority within one’s self” (p. 80) and her subsequent decisions to “conquer [her] fears and not let them block [her] way” (p. 77) and to “improve” herself (p. 104). Jim (Prince-Hughes, 2002) described his discovery and a subsequent decision as follows:

I read the works of Jack London and came away with the thought that among wolf-packs “to be different was to be dead.” The closest analogy I had at the time to the human behavior I observed around me was the behavior of wolf-packs; it was obvious to me I
would have to change. It was no longer enough to try to understand the society around me—I had to learn how to no longer stand out, no longer be weird. (pp. 68–9)

Jerry Newport (2001) made a similar observation: “When my self-discovery began, I fantasized about living on a planet of people like me. But I decided that I had to learn to negotiate better with the majority of Earth’s residents” (p. 11).

Following their discoveries about “being different” from others, many other autistic individuals embarked on a conscious study of social behavior by carefully observing, “listen[ing] intently to other people’s conversations and mak[ing] mental notes” (N. Jackson, 2002, p. 17) and subsequently consciously copying others in an effort to “act normal” (e.g., Dumortier, 2004; Gerland, 1997; Grandin & Scariano, 1986; Holliday Willey, 1999; McKean, 1994; Prince-Hughes, 2002, 2004; Spicer, 1998a, 1998b).

Following their self-discoveries, others made decisions about “fighting,” “controlling,” and waging wars on autism. For example, Donna Williams (1994) concluded the second installment of her autobiography in the following way:

The most important thing I have learned is that AUTISM IS NOT ME. . . .

The second most important thing I have learned is I CAN FIGHT AUTISM . . . [ellipsis in original] I WILL CONTROL IT . . . [ellipsis in original]

IT WILL NOT CONTROL ME [original formatting]. (p. 238)

Sean Barron (Grandin & Barron, 2005) made a similar discovery: “I understood for the first time that I was capable of working to become the person I wanted to be” (p. 76), as well as a subsequent decision to wage a “war” on his autistic obsessions:

I took a look at myself in a way I had never done before, and this is what I saw; I had problems, real ones, big ones. But that didn’t mean that there was something fundamentally wrong with me, that I was unlike everybody else in the world. I knew that I was separate from my problems I had and that I could overcome them. I declared war! I was going to fight against all the behaviors I had obeyed all my life. . . . Dead-end streets and bus numbers still went round and round in my head, and I pushed them out—I made myself think other thoughts instead. (p. 232)
Like Dawn, Donna, Sean, and others, Bill Kolinski (1995) also discovered the power of the belief that change is not only desirable but also possible. As he put it:

> Perhaps I had been learning-disabled and was slow in ways, but if you set your heart and mind on a goal like I did, nothing can stop you from success in your own eyes, despite circumstances you have little or no control over. You aren’t teachable and maturable unless you believe yourself to be, and will it. (pp. 197–198)

But changing oneself was not easy for autistic individuals. As Sean Barron (Grandin & Barron, 2005) put it, “It took . . . many years’ worth of trials, setbacks, triumphs, gains, pain, heartache, hard work, determination and practice, for me to gain the upper hand on my autism” (p. 60). Likewise, Marc Fleisher (2003) wrote, “Behind every one of my major achievements is a long list of smaller ones, which had to be mastered step by step. And behind every one of those was required a great deal of sacrifice, pain, planning and willpower” (p. 24). Indeed, hard work, determination, and perseverance are either implicit or explicit in almost all autobiographies of autistic individuals.

Another factor sometimes identified by autistic individuals as contributing to their success is social support, usually from their families (e.g., Grandin & Barron, 2005; Grandin & Scariano, 1986; Fleisher, 2003; Tammet, 2007), and, less often, from teachers (Grandin & Scariano; Nazeer, 2006) or others (Prince-Hughes, 2004). For example, Sean Barron (Grandin & Barron, 2005) wrote, “I give my family as much credit as I give myself for creating the conditions that allowed me to come out” (p. 60). However, it is important to note that, according to autobiographical accounts, families of successful autistic adults were not always supportive. Indeed, in several instances families were apparently unsupportive, neglectful, and even abusive (e.g., Gerland, 1997; McKean, 1994; Robison, 2008; D. Williams, 1992).

However, in weighing the importance of self-related and others-related factors, some autistic individuals feel that the former are more important. They argue that no amount of support in itself guarantees success, rather, it is the autistic person who has to use the opportunities provided by others. As Bill Kolinski (1995) put it: “Schools and teachers offer knowledge, skills, and guidance; it’s up to you to take the initiative, open yourself up and apply it to create who and what you believe you are best meant to be” (pp.197–98).
With regard to the quality of their lives, autistic autobiographers, for the most part, seem satisfied with their educational achievements, mastery, and expertise in their chosen fields (e.g., Fleisher, 2003; Grandin & Barron, 2005; Holliday Willey, 2001; Kolinski, 1995; Prince-Hughes, 2004; Robison, 2008; Shore, 2001; Tammet, 2006; Williams, 2004b). To quote Liane Holliday Willey (2001), “I am happy for my tenacious interest in my intellectual pursuits. I am proud of the knowledge I possess and I am always anxious to learn even more” (Holliday Willey, 2001, p. 152). Temple Grandin (1995c) described it as follows:

I feel a deep satisfaction when I make use of my intellect to design a challenging project. It is the kind of satisfied feeling one gets after finishing a difficult crossword puzzle or playing a challenging game of chess or bridge; it’s not an emotional experience so much as an intellectual satisfaction. (p. 88)

As previously mentioned, autistic authors also seem to be content with the kind of persons they are, which they see as part of what it means to be autistic: they highly value their creativity, honesty, meticulousness, loyalty, and their desire to be helpful and make positive contributions to society (e.g., Grandin & Barron, 2005; Holliday Willey, 2001; Prince-Hughes, 2004; Robison, 2008; Shore, 2001; Tammet, 2006; Williams, 1998). Liane Holliday Willey (2001) even created a special word to capture her feelings about being an autistic person (i.e., a person with Asperger syndrome), “aspie.” She wrote, “I like my life defined by the noun, aspie”:

To my mind, being an aspie means being able to ferret out details that might otherwise go unknown. It means searching for reason and logic and truth behind the hidden . . . It means loyalty to those people and those ideas we care about. It means tenacity and perseverance despite the hills and the valleys. And it means different . . . [ellipsis in original] not less, not bad, not unworthy or incapable . . . [ellipsis in original] just different. (p.155)

On the other hand, autistic individuals are mostly, although not universally, dissatisfied with their social relationships, romantic ones in particular. For example, David Miedzianik (1986) repeatedly expressed his dissatisfaction over not having friends and romantic relationships throughout his autobiography. In one instance he wrote,

Recently things have really got me down. I am 28 years old and most of the friends I went to school with are married and no-one ever goes out with me much. I have been meeting a few girls recently, but there is nothing in it, I don’t think, with any of them. I
would really like to meet someone, but being without a job all the time makes it hard for me to make friends. Recently in about this last year or so I have been writing letters to the radio; I have had my letters read out on Radio One quite a bit. I keep thinking if I get things read out on the radio I might make some new friends. Things really get me down, wandering around Rotherham most of the time by myself. Not having any girls that like me really makes me sad. . . . I feel depressed at not having any girlfriends. (p. 95)

Rather obviously, the lack of satisfactory social relationships made many autistic autobiographers feel unhappy with their lives in general. For example, David Miedzianik (1986) summed up his life as follows:

Living is more or less one constant bore. I think if it wasn’t for the writing I don’t think I would have been alive, I think I might have ended it all; but this writing has somehow given me some reason to carry on. (1986, p. 101–2)

In concluding his autobiography, David wrote,

Someone says I should have written about the moods I have, but I think I have described fairly well why I think a lot that’s happened to me is enough to make anyone moody. Yes, I think anyone normal would find it hard to lead the kind of existence I have. I think if some normal girl would take an interest in me I would just bother with her and no other girl, but I spend my time talking to a lot of girls, hoping I can find one that will take a real interest. Well, I think that really is the last I will write. (Miedzianik, 1986, p. 103)

Like David, Dominique Dumortier (2004) also expressed dissatisfaction with her life, which largely stemmed from a feeling of not belonging. In her autobiography, fittingly titled From another planet: Autism from within, she wrote, “My autism often makes me feel very unhappy. It is tough to be confronted all the time with having no hold over anything and being unable to take part in the world” (p. 95). However, unlike David, who is hopeful about the future, Dominique concluded her autobiography on a more pessimistic note:

I feel as if I don’t come from Earth but from another planet. I don’t belong here. I’m not at home here. I’m a counter magnet. It’s not easy to say this but that’s how it feels. . . . I don’t understand the world and the world doesn’t understand me. I’m angry at the world and the world is angry with me. I’m not allowed to be a part of the world, but I still fight for the privilege, even though I know I will never win. I’m different and there’s no room for me. The harder I try, the more frustrated I get. I will always be separate from the rest. I will remain separate from that big, unattainable world. I will stay on my own planet. (p. 97)
In contrast, many autistic authors expressed satisfaction with both their social relationships and their lives in general (Grandin & Barron, 2005; Holliday Willey, 2001; Newport, 2001; Prince-Hughes, 2002; Robison, 2008; Shore, 2001; Tammet, 2006; D. Williams, 2004a). For instance, Jerry Newport (2001) wrote, “I know that my life now is as good as it can be and will continue to be that way because I love myself enough to guarantee that” (p. 292). Likewise, Dawn Prince-Hughes (2002) felt that her “life is perfect and that I am perfectly fine the way I am” (p. 122).

In summary, autobiographical accounts of autistic individuals provide some support to Kanner and his colleagues’ (1972) suggestion that self-understanding and conscious efforts at changing one’s maladaptive autistic tendencies might be crucial for successful outcomes. In addition, social support in its various forms seems to be beneficial, although it does not appear to be crucial. Moreover, although there are many similarities across autobiographical accounts with regard to factors that made a difference, it is important to emphasize that there were no two identical life paths to success. As Temple Grandin and Sean Barron (2005) noted with respect to their own lives, “Two very different paths, yet we both arrived at the same destination: happy independent adults, with satisfying jobs and personal relationships that provide us with a sense of connection and belonging” (p. xvi). Finally, as suggested by Temple Grandin and Sean Barron, amongst others, some autistic adults are also happy people satisfied with their lives.
3 Intentional Personal Development

The lifespan psychology approach to development recognizes that human development depends not only on biology and culture (as epitomized in the nature-nurture debate) but also on the developing person (Greve & Staudinger, 2006). Moreover, according to Brandtstädtter (Brandtstädtter, 1989; Brandtstädtter & Lerner, 1999), individuals’ influences on their own development are crucial. Greve and Staudinger also suggest that personal influences become increasingly important with age. In this study, I use the term intentional personal development to refer to these personal influences on one’s development. The term itself is a variation on Brandtstädtter and his colleagues’ (Brandtstädtter & Rothermund 2002; Brandtstädtter, Wentura, & Rothermund, 1999) notion of intentional self-development and Ferrari and Mahalingam’s (1998) notion of personal cognitive development. This concept is intended to integrate two broad factors identified in the above-reviewed clinical and autobiographical literature as potentially relevant to life outcomes for autistic individuals: self-understanding and future orientation. Intentional personal development is akin to Hacking’s (1986b) notion of self-improvement (i.e., “work on oneself with the regard to the possibilities of . . . becoming something different from what we have been made” (p. 233).

In addition to the person’s active role, another important feature of intentional personal development is its intimate connection to values (i.e., beliefs about what would be good to become). In other words, by taking active roles in shaping their lives and the kind of persons they become, people “work” not only towards what is possible (as Hacking, 1986b, suggested), but also towards what is desirable (as implied in philosophical notions of the “care for the self” and “taking ourselves seriously,” Foucault, 1978, and Frankfurt, 1988, 2004, respectively). Therefore, because intentional personal development implies taking a moral stand on one’s life, it is closely tied to peoples’ understanding of the meaning of their lives (Ferrari & Vuletic, in press; King & Napa, 1998; Seligman & Csikszentmihalyi, 2000).
3.1 Role of Intentional Personal Development in Successful Life Outcomes

Different aspects of intentional personal development (e.g., self-understanding, self-esteem, self-efficacy, self-acceptance, agency, and locus of control) are often cited in the psychological literature as factors contributing to good life outcomes (e.g., Csikszentmihalyi, 1996; Gardner, 1997; Sternberg & Spear-Swerling, 1998; Terman & Oden, 1959). According to Sternberg and Spear-Swerling (1998), people will be successful in life if they have an adequate awareness of their strengths and weaknesses, needs, desires, and goals, and if they know how to compensate for their weaknesses and capitalize on their strengths—what they call “personal navigation.” Likewise, Csikszentmihalyi (1996) argued that individuals who make significant cultural contributions are distinguished from others—with similar levels of abilities, supportive environments, and good luck—by their personal resolution[s] to shape their lives to suit their own goals instead of letting external forces rule their destiny. Indeed, it could be said that the most obvious achievement of these people is that they created their own lives. (pp. 151–2)

The importance of self-understanding, positive self-esteem, sense of self-efficacy, and the ability to plan ahead have also been often highlighted in the literature on resilience—a capacity or process by which people avoid negative outcomes of development despite significant risk factors, developmental setbacks or crises (Masten, 1994; Masten, Best, & Garmezy, 1990; Rutter, 1985; Werner, 2005; Werner & Smith, 2001). Likewise, the literature on recovery from mental disorders suggests that an active sense of self, self-acceptance, self-confidence, self-determination, and looking forward may be crucial for good life outcomes for individuals diagnosed with mental disorders (L. Davidson, 2003; Farkas, 2007; Jacobson & Greenley, 2001; Wexler, Davidson, Styron, & Strauss, 2007). However, empirical evidence about the contributions of such factors related to intentional personal development for life outcomes is scant.

In a recent qualitative study, Hauser, Allen and Golden (2006) found that adolescents with serious emotional and behavioral difficulties (requiring years of institutional psychiatric treatment) made pivotal changes in their lives through “work within themselves to create
environments and relationships that . . . supported healthy growth” (p. viii). More specifically, Hauser and colleagues found that self-reflection and personal agency, as well as commitment to social relationships, played crucial roles in life changes of individuals who achieved “better than expected” life outcomes.

Similarly, L. Davidson and colleagues (2003; L. Davidson et al., 2005; L. Davidson & Strauss, 1992) reported that self-understanding (including self-acceptance), self-efficacy, and future orientation were also among crucial factors that contributed to the recovery from schizophrenia and other mental disorders. According to L. Davidson and Strauss, recovery is a process of reconstructing the self in the following four steps: (a) emergence of the idea that things can change; (b) evaluation of possibilities for change; (c) action based on a new sense of agency; and (d) enhanced sense of control and efficacy, which further promotes more advanced forms of positive action.

### 3.2 Intentional Personal Development in Autism

As mentioned earlier, there are no studies that have explored intentional personal development in autistic individuals. In this section, I will briefly review what is known about the core elements of intentional personal development—self-understanding, future orientation, and self-efficacy—in autism.

#### 3.2.1 Self-Understanding in Autism

It is widely recognized that self-understanding is important for how we live our lives (e.g., Staudinger, 2001; Sternberg & Spear-Swerling, 1998). Moreover, self-understanding has been shown to be of crucial importance for psychosocial adaptation in clinical populations, such as individuals with emotional and behavioral problems (Hauser et al., 2006), conduct disorder (C. R. Rogers, Kell, & McNeil, 1948), schizophrenia (L. Davidson, 2003), depression and other mental disorders (L. Davidson & Strauss, 1992). However, as already mentioned, the role of self-understanding in the life outcomes of autistic individuals has never been empirically explored. At
least one of the reasons for this could be the persistent theoretical claims that autistic individuals lack self-awareness and are deficient in their ability to understand themselves (e.g., Baron-Cohen, 1989b; Bettelheim, 1967; Fordham, 1976; Frith, 1989, 2003; Frith & Happé, 1999; Hobson, 1993; Jordan, 1997; Mahler, 1952, 1958; Mahler & Furer, 1968; Meltzer, Bremner, Hoxter, Weddell, & Wittenberg, 1975; Powell & Jordan, 1993; S. J. Rogers & Pennington, 1991; Tustin, 1972).

3.2.1.1 Theoretical Accounts

Since the earliest psychoanalytic theoretical accounts of autism, it has been postulated that there is something wrong with autistic individuals’ self-understanding (variously referred to in autism literature as the lack of self-awareness, self-consciousness, self-concept, sense of self, self, ego, or identity; L. C. Mayes & Cohen, 1994). As previously mentioned, Mahler (1952, 1958; Mahler & Furer, 1968) viewed autism as a disorder of the ego, or of identity, and suggested that it stems from infants’ inability to differentiate representations of the self from those of others (the mother in particular). Bettelheim (1967) further claimed that an “autistic child does not attribute events to his personal activity” and is thus “completely unaware of [himself] as a subject” (pp. 444–45). Likewise, for other psycho/analytically oriented scholars, autism was associated with a lack of an integrated sense of self (Fordham, 1976; Meltzer et al., 1975), a lack of “a sense of personal identity” (Tustin, 1969, p. 31), or a lack of “awareness of being a ‘self’” (Tustin, 1972, p. 1). As Tustin (1972) put it,

> Autism literally means living in terms of the self. To an observer, a child in a state of autism appears to be self-centred since he shows little response to the outside world. However, paradoxically, the child in such a state has little awareness of being a “self.” (p. 1)

More recently, several authors working within the theory of mind model also proposed that autism entails “little awareness of being a ‘self,’” or, in this new language, “a lack of theory of own [italics in original] mind” (Frith & Happé, 1999, p. 1). According to this model, which originates in Premack and Woodruff’s (1978) “theory of mind” concept—which refers to the ability to attribute mental states to self and others—the “theory we apply to others’ minds is exactly the same as we apply to our own mind” (Frith, 1989, p. 168). Consequently, because in
autism understanding of others is impaired, by “logical extension” (p. 7), understanding of oneself must therefore also be impaired. In other words, according to the “hypothesis of poor self-awareness” in autistic individuals (Frith, 1989), “the ability to make sense of other people is also the ability to make sense of one’s self” (p. 169). Therefore, “if the development of a theory of mind is problematic for autistic children, then it follows that the development of their self-awareness may also be problematic” (p. 169). Indeed, because “to the autistic individual . . . mental states, such as [emotions], knowing and believing, are . . . a mystery” (p. 168), self-awareness must be an impossibility. In summary,

The hypothesis of poor self-awareness [in autism] concerns . . . the development of an appropriate representation of the self as owner and manipulator of mental states. If this mental self is a product of reflection—then without the ability to reflect on mental states it may not exist. (p. 169)

Consequently, Frith (2003) suggested, because this “mental,” or “self-aware self,” does not exist in autistic individuals, autism is best understood as “an absent self” (p. 208).

In his extension of the theory of mind hypothesis of autism, Baron-Cohen (1989b) also claimed that autistic individuals are incapable of self-reflection and introspection, and, consequently, of providing self-report. As he put it, “many autistic children can talk fluently about the physical, outer world, but lack concepts of mental states necessary to be able to talk about the inner world” (p. 197). Accordingly,

there are no data available relating to the autistic child’s subjective evaluation of [his/her] experiences, and recent cognitive evidence (Baron-Cohen, Leslie & Frith, 1985, 1986) suggests that there never will be [emphasis added], as autistic children seem unable to conceive of their own or other people’s mental states. (p. 195)

Similarly, Powell and Jordan (1993) contended that autistic individuals have a “deficit in developing an ‘experiencing self’ (an ego-self)” (p. 362). Indeed, such self, they suggested, “may not exist” in autism (p. 366). According to them, this deficit has a number of cascading consequences:

the lack of an ego-self has a profound effect at all stages in the processing of information. At the perceptual stage, events would be experienced but in a non-subjective way, that is,
individuals with autism would be aware of what was happening but not aware that it was happening to them [italics in original]. (p. 362)

As a result, autistic individuals would not be able to remember their experiences as personally experienced but only as “knowledge” of facts about them that they acquired from others. Jordan (1997) further argued that “the individual may have a concept of him/herself but it is limited to autobiographical knowledge, knowing oneself from the ‘outside’ as it were” (p. 21). This lack of personal memory has further consequences on “self expression [which is] limited to what others have ‘fed in’” (p. 21), as well as on one’s ability to self-reflect.

In fact, the belief that autistic individuals lack self-awareness and are incapable of self-reflection has been held so strongly that, when autobiographical accounts of autistic individuals started to be published in the mid 1980s, the scientific community expressed its disbelief as to their validity. For example, Frith and Happé (1999; Happé, 1991) warned about taking autistic individuals’ autobiographical accounts at their “face value” (Frith & Happé, 1999, p. 18). Indeed, Happé wondered, “Is it not probable . . . that an autistic child will have peculiarly unreliable memories from a childhood without self-awareness?” (p. 222). Sacks (1995) summarized the implications of this widely held assumption that autistic individuals are “handicapped and not able to present their own side of things” (Frith & Happé, 1999, p. 2) as follows:

When I first read the book [Temple Grandin’s autobiography, Grandin & Scariano, 1986], I could not help being suspicious of it: the autistic mind, it was supposed at the time, was incapable of self-understanding and understanding others and therefore of authentic introspection and retrospection. How could an autistic person write an autobiography? It seemed a contradiction in terms. (p. 253)

Interestingly, despite the many autobiographies written by autistic individuals since 1986, the view about autobiographies of autistic individuals has not changed. This is best reflected in Sacks’ more recent comment on another (this time nonverbal) autistic person’s autobiography (Mukhopadhyay, 2003). He wrote,

The book is indeed amazing, shocking too, for it has usually been assumed that deeply autistic people are scarcely capable of introspection or deep thought, let alone of poetic or metaphoric leaps of imagination—or if they are, that they are incapable of communicating these thoughts to us. (back matter)
3.2.1.2 Empirical Evidence

Despite the seriousness of claims of an absent self-awareness in autism, very few studies have empirically explored the self-understanding of autistic individuals (Bauminger, Shulman, & Agam, 2004; Capps, Sigman, & Yirmiya, 1995; Hobson, Chidambi, Lee, & Meyer, 2006; Hurlburt, Happé & Frith, 1994; Lee & Hobson, 1998; Tan & Harris, 1991). In one study, using a method adapted from Damon and Hart (1988) to explore autistic children’s and adolescents’ self-descriptions, Lee and Hobson (1998) found that autistic subjects differed from control subjects in the frequency and quality of their self-descriptions in relation to others (i.e., social self) but not in their descriptions of their psychological, physical, and activity-related features (i.e., psychological, physical, and active self). More recently, Hobson and his colleagues (2006) investigated autistic adolescents’ understanding of two social emotions, pride and guilt, that are believed to depend on self-awareness, and reported that, contrary to the researchers’ predictions, there were no significant group differences in participants’ ability to report on their own experiences of these emotions. In another study, Tan and Harris (1991) explored autistic children’s understanding of their own desires and found them no different from that of control subjects.

Three studies explored high-functioning autistic children’s and adolescents’ self-esteem (Bauminger, Shulman, & Agam, 2004; Capps, Sigman, & Yirmiya, 1995; Williamson, Craig, & Slinger, 2008) using Harter’s scales (1982, 1985); all three found that, compared to non-autistic subjects, autistic subjects described themselves as less competent in social acceptance but not in scholastic or cognitive abilities, which is broadly consistent with a third-person’s view of autistic individuals. Two studies (Bauminger et al., 2004; Williamson et al., 2009) also provide converging evidence with regard to autistic individuals’ lower estimates of their athletic competence (which was not explored by Capps et al., 1995), which is also broadly consistent with a third-person’s view of autistic individuals. The evidence with regard to other domains is

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10 When comparing the findings across these studies, it is important to keep in mind that two different versions of the instrument for measuring self-competence were used: Capps and her colleagues (1995) used the Perceived Competence Scale for Children (Harter, 1982) which has three subscales (Cognitive, Social, and Physical), while Bauminger and colleagues (2004) and Williamson and colleagues (2008) used a newer Self-Perception Profile for Children (Harter, 1985), which has six subscales (scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct, and a general domain of global self-worth).
less clear. More specifically, Capps and colleagues (1995) also found differences in the physical
domain and in overall self-worth, whereas Bauminger and colleagues (2004) and Williamson and
colleagues (2008) did not.

Only one study has specifically explored the self-understanding of autistic adults. Using an
experience sampling method that involved beepers to signal subjects as to when to make a note
about their ongoing mental contents, Hurlburt and colleagues (1994) explored the introspective
abilities of three adults with Asperger syndrome. Two subjects successfully completed the task
by reporting vivid images, and although the third was not able to report his ongoing mental
contents using the beeper method (instead always reporting his physical actions), he was,
evertheless, able to discuss his ongoing inner experience during interviews. Here is an
experience sample:

Robert was at home watching football on TV with his mother. He hated football and was
“thinking about how to get around watching it”. At the moment of the beep, he was
seeing an image of himself sitting on the floor playing with his mother’s cat. (Frith &
Happé, 1999, p. 12)

However, because other participants previously tested with the same technique reported more
varied inner experiences, including inner speech, feelings, and “unsymbolized thinking,” in
addition to images, Hurlburt and colleagues (1994) concluded that autistic individuals’
introspective abilities were markedly different in quality than those of others.

Taken together, these studies show that although some aspects of autistic individuals’ self-
understanding may be atypical, their self-understanding does not appear to be as impaired as is
often claimed. The converging evidence from several studies about their lower estimates of
social and athletic, but not cognitive, competences matches perfectly the current diagnostic
criteria for high-functioning autism (i.e., social incompetence with intact cognitive abilities is
their defining feature, whereas motor impairment is an associated feature), suggesting that
autistic individuals’ self-understanding of their competences is unimpaired.

However, despite this evidence, proponents of self-understanding deficit hypotheses in autism
have not modified their views. For example, considering the evidence they collected, Hobson
and colleagues (2006) concluded that although “there is certainly not a total absence of self-ascription” in autism (p. 75), self-understanding of autistic individuals is not as deep, and as thick, as that of their peers (i.e., it is limited to “lower” levels of self-understanding). They wrote, “At least some individuals with autism acquire a concept of self . . . but their concept of self appears somewhat thin” (p. 149). Moreover, they stated, “although it is clear that persons with autism can say something relevant to self-experience, it remains uncertain just how deeply they have a sense of themselves as selves, and therefore how far their reflections are truly self-reflective” (p. 134). Hobson (2002/2004) previously also claimed that autistic individuals do not have “the right kind of self” (p. 211) and that their selves “float unanchored” (p. 210). Likewise, despite the contrary evidence Frith and Happé (1999) obtained in their study of introspective abilities of autistic individuals (reviewed above; Hurlburt et al., 1994)—and after admitting that “while we had expected a relative inability to think and talk about inner experience, this was true for only one of the subjects” (Hurlburt et al., p. 393)—they still maintained that autistic individuals lack a “theory of *own* [italics in original] mind” (p. 1).

Nevertheless, regardless of these continuing claims of impaired self-understanding in autism (even in the absence of hard evidence), available empirical evidence clearly suggests that at least some autistic individuals can both self-reflect and provide self-reports.

It is also important to emphasize that the main focus of the above-reviewed studies was to discover how self-understanding of autistic individuals differs from that of control subjects—not to shed light on how autistic individuals understand themselves as autistic individuals (i.e., as individuals endowed with specific challenges they need to overcome in order to function well in a society), which Kanner and colleagues (1972) suggested was important for the positive outcome of autistic individuals.

However, several case studies, including my own MA thesis (Vuletic et al., 2005), have documented autistic individuals’ unique experiences of being autistic and provide some insight as to how autistic individuals make sense of their life experiences—including their unique (i.e., not shared with typical populations) feelings of constant confusion, awkwardness, “badness,” and frustration brought about by their social experiences, such as a lack of understanding by
others, social isolation, social exclusion, and victimization (Bemporad, 1979; Cesaroni & Garber, 1991; Molloy & Vasil, 2002; Volkmar & Cohen, 1985).

3.2.1.3 Autobiographical Evidence

Despite the above-mentioned theoretical claims about autistic individuals’ autobiographies, this material provides invaluable information about autistic individuals’ understanding of themselves as complex human beings living in the real world (as opposed to their self-statements in response to strangers’ questions in a testing room). Moreover, the already-reviewed autobiographical evidence shows that, contrary to the claims of Baron-Cohen (1989b), Frith and Happé (1999), Hobson and colleagues (2006) and others, autistic individuals can provide self-reports that “present their own side of things” and say more than just “something relevant to self-experience.” Above all, autobiographical evidence clearly indicates that autistic individuals are not “absent selves” walking around, as Frith (2003) contended, nor do they necessarily lack a “theory of own mind,” as Frith and Happé (1999) suggested; the following quote certainly seems like a clear instance of having a theory of one’s own mind, although—curiously enough—it is cited by Frith and Happé in support of their hypothesis that states the opposite:

I was sick to death of my attention wandering onto the reflection of every element of light and colour, the tracing of every patterned shape and the vibration of noise as it bounced off the walls. I used to love it. It had always come to rescue me and take me away from an incomprehensible world, where, once having given up fighting for meaning, my senses would stop torturing me as they climbed down from overload to an entertaining, secure, and hypnotic level of hyper. This was the beautiful side of autism. (D. Williams, 1994; as cited by Frith & Happé, pp. 112–113)

In summary, from the above-presented evidence, it seems reasonable to conclude that despite the longstanding theoretical claims to the contrary, the available evidence, both empirical and autobiographical, suggests that autism does not preclude people from understanding themselves as people with unique experiences, needs, desires, strengths, and weaknesses, nor does it preclude them from evaluating their past and present experiences. However, although intentional personal development needs this sort of self-understanding, it is not sufficient; intentional personal development also requires an orientation toward the future, considered next.
3.2.2 Future Orientation

Future orientation involves thinking, feelings, and behaviors oriented toward what could be—including having plans, daydreams, and hopes, as well as a belief that what has been imagined could actually happen (Aspinwall, 2005; Nurmi, 1989; Seginer, 2009; Zimbardo & Boyd, 1999). The importance of future-orientation for psychosocial adaptation and psychological well-being has long been recognized in psychology (e.g., Allport, 1937; Aspinwall, 2005; Bandura, 1977, 1989, 2001; Erikson, 1959/1980, 1968; Lewin, 1935, 1939; Moore & Lemmon, 2001; Seginer, 2009; Sullivan, 1953). Future orientation has also been proposed as a driving force of personal change (Allport, 1937; Higgins, 1987). Moreover, several studies (e.g., L. Davidson et al., 2005; Dunkel, Kelts, & Coon, 2006; Hauser et al., 2006) have found future orientation to be one of the crucial contributing factors for good outcomes in clinical populations. On the other hand, a lack of orientation towards the future has been associated with negative outcomes, such as maladjustment (Klineberg, 1967), delinquency (Oyserman & Markus, 1990), and prolonged depression (Lyubomirsky & Nolen-Hoeksema, 1995; Nolen-Hoeksema & Morrow, 1993).

To the best of my knowledge, there are no studies that specifically investigated future orientation in autism. However, on the basis of the existing empirical literature on autistic “impairments” in cognitive abilities thought to be necessary for future orientation, such as, for example, poor executive functions (Hill, 2004; Ozonoff, 1995) and imagination (J. Craig & Baron-Cohen, 1999), it is usually assumed that future orientation of autistic individuals is also impaired. Moreover, some proponents of the self-awareness deficit hypothesis in autism argued that impairment in future orientation of autistic individuals is a direct byproduct of their lack of a sense of self. As Jordan (1997) put it, a “failure to establish an ‘experiencing self’” means that “there will be problems in developing a sense of agency. This will lead in turn to . . . an inability to be aware of intentions and therefore to plan actions, [and] a lack of goal-directedness in actions” (p. 21).

Yet, the clinical and autobiographical evidence clearly suggest that this is not necessarily so (e.g., Barron & Baron, 1992; Fleisher, 2003; Grandin & Scariano, 1986; Kanner et al., 1972; Kolinski, 1995; Newport, 2001; Prince-Hughes, 2004; D. Williams, 1992, 1994, 1996b, 1998). Moreover, as already reviewed, evidence suggests that future orientation played an important
part in psychosocial adaptation of at least some autistic individuals who have adjusted well. In addition to many references to plans, wishes, hopes, daydreams, and aspirations, these autistic individuals also wrote about the goals they had for themselves and how those goals motivated them to do better and to change, and how they used their visions of their futures as life guides.

In fact, Jerry Newport (2001) devoted several concluding pages of his autobiographical guidebook *Your life is not a label: A guide to living fully with autism and Asperger’s syndrome for parents, professionals and you!* to sharing his insights about the importance of future orientation for life success. He wrote,

> If you want your last day in this world to be a good one, positive, triumphant and inspiring to all who witness it, then you must work now like me to make that a certainty, barring accidents.

> How do you do that? As I have said many times in this book, planning is your greatest friend. . . . You always need to have a plan. You need to decide what experiences are ones that you really want and can have. (p. 289)

In conclusion, it is surprising how little is known about the future orientation of autistic individuals, particularly in light of the overwhelming evidence about its importance for psychosocial adaptation. Although the existing autobiographical evidence provides some support for Kanner and his colleagues’ (1972) contention that future orientation, along with self-understanding, might be necessary for a good life outcome for autistic individuals, a substantial body of empirical evidence in its support is still lacking.

### 3.3 Summary

In this section, based on the review of the clinical and autobiographical literature, it is proposed that intentional personal development (i.e., including both self-understanding and future orientation) could be a useful construct for understanding life outcomes of individuals. However, although processes constitutive of intentional personal development, such as self-understanding, self-discovery, and goal-setting, are often described by successful autistic individuals—based on these accounts alone—it is not possible to conclude whether these processes necessarily led to the good life outcomes of these individuals, nor whether they are necessary for all autistic
individuals to successfully adjust. One way to increase our understanding of these processes and their potential role in life outcomes of autistic individuals is through an in-depth interview study of autistic adults with different levels of both psychosocial adjustment and intentional personal development. However, because it is frequently claimed—and usually assumed—that autistic individuals cannot provide a valid self-report, this section also provided grounds for claiming that these assumptions are false and that autistic individuals are clearly capable of providing valid first-person evidence about their life experiences. Given this background, the next section presents the rationale, aims, and research questions of the current study.
4 Rationale, Aims, and Research Questions of This Study

There is great variability in outcomes among high-functioning autistic individuals: while some achieve life success, according to both their own and societal criteria, others do not appear to lead good lives—by any criteria. Not much is known about the factors that contribute to this variability, nor is much known about what autistic individuals consider a good life to be. However, the available autobiographical evidence suggests that intentional personal development may play an important, if not a crucial, role in the life success of autistic individuals.

Although clinical and autobiographical accounts are important sources of information about the factors that might facilitate good life outcomes, they suffer from a number of limitations. Most of the available clinical and autobiographical accounts are about or by autistic individuals who attained good life outcomes and not much is known about how their lives differed from those of individuals who did not achieve such outcomes. Therefore, it would be important to compare the life histories of autistic individuals with different life outcomes.

Another limitation of autobiographical evidence is that each autobiography has a different frame of reference—each has been written to convey only what the authors felt was important for the story they wanted to tell—which may leave some important influences out of the account. This selectivity makes comparison of autobiographies difficult. Therefore, it would be important to obtain a uniform set of data that could lend itself to comparisons.

The main aim of this study is to begin to understand the factors that may facilitate good life outcomes for autistic individuals. Although the study explores all influences that the participants believe were, or could have been, significant in their lives, special focus is placed on the factors already identified by autistic individuals and clinicians in existing literature as potentially crucial for autistic individuals’ life outcomes. To this end, I explore four aspects of intentional personal development, two related to self-understanding and two related to future orientation. I explore self-understanding through (a) autistic individuals’ conceptions of themselves and (b) their
meaning-making of past experiences. I explore future orientation through (a) autistic individuals’ imagined future and (b) their self-efficacy beliefs (i.e., beliefs about the extent to which they can accomplish the goals they set for themselves).

This study has two additional aims. First, to collect descriptive information about autistic adults’ lived experiences—particularly those they consider to be the most significant in their lives. This is an important aim because the vast majority of autism research has been theoretically driven, and there is a paucity of research documenting lived experiences of autistic adults. In addition, as already mentioned, autism research has traditionally focused on children, and research on autistic adults has only recently started to become more common.

The final aim of this study is to explore autistic adults’ conceptions of a good life outcome. All existing research on the life outcomes of autistic individuals has been done from a one-size-fits-all perspective in which a good life means living independently, having a job, and having personal relationships. However, when we consider how well autistic individuals have adjusted to the world, it is also important to consider what “good life” means to them. These aims can be summed up in the following set of questions that guided the interviews conducted:

1. (a) How do autistic adults describe themselves?
   (b) How do autistic adults make meaning of their autism?
2. (a) What are autistic adults’ most significant life experiences?
   (b) How do autistic adults make meaning of their life experiences?
3. (a) How do autistic individuals live?
   (b) How satisfied are autistic individuals with their lives?
4. (a) What does a desirable future of autistic adults look like?
   (b) What would a “better world” for autistic individuals be?
5. (a) What are the perceived favorable significant influences in the lives of autistic individuals?
   (b) How important is intentional personal development for the life outcomes of autistic individuals?
Chapter 2 Method

5 Approach and Design

A method of a study should be driven by its problematic (Elliott, Fischer, & Rennie, 1999; Flyvbjerg, 2006; Habermas, 1968/1971; Patton, 2002). In other words, a best method is one that “best help[s] answer the research questions at hand” (Flyvbjerg, 2006, p. 241). Given this study’s stated aims and research questions, I believe it is most appropriate to use a qualitative approach and a case study design. Next, I briefly review the main characteristics of this approach and design.

5.1 Qualitative Approach

Qualitative approach refers to diverse research traditions aiming to understand subjective experiences and their meanings for individuals (Camic, Rhodes, & Yardley, 2003; Clandinin & Connelly, 1994; Patton, 2002; J. A. Smith, 2003). Three traditions particularly relevant for this project are phenomenology (Giorgi, 1985; Moustakas, 1994; van Manen, 1998), hermeneutic or interpretive phenomenology (Smith & Osborn, 2003), and narrative inquiry (Polkinghorne, 1988). In contrast to quantitative research, which seeks to uncover the universal truth, qualitative inquiry aims to discover multiple truths or interpretations of reality (Flyvbjerg, 2006; Guba, 1981). To this end, its first task, particularly emphasized by phenomenological approaches, is to provide subjective meanings, or personal realities of participants in the form of “thick” (i.e., detailed) descriptions. Its second task, emphasized by hermeneutic approaches, is to provide interpretations of the data by putting them into a broader context using existing knowledge from a variety of sources. In addition to qualitative inquiry’s unique suitability for providing insight into the personal realities of autistic individuals, its two other characteristics are also relevant to the aims of this study: (a) its suitability for grasping the complexity of the phenomena (Flyvbjerg, 2006; Peshkin, 1988); and (b) its openness to the unknown, unexpected, and unsuspected (H. S. Becker, 1996; Strauss & Corbin, 1998; Way, 2005).
Given that one of the aims of this study is to gain an understanding of autistic individuals’ life experiences and the meanings they ascribe to them, a qualitative approach is most suitable. Moreover, the complexity and connectedness of issues explored (e.g., participant’s views of themselves as persons, their autism, their past, present, and future lives; as well as the ways they constructed these views), and their grounding in real-life are also best explored by qualitative methods. Finally, although the existing literature provides some guideposts with regard to potential determinants of life outcomes of autistic individuals (e.g., self-understanding and future orientation), there is no reason to believe that these are the only ones involved. Indeed, the research on human development clearly indicates that the variation in outcomes cannot be explained by any one single factor (Wachs, 2000). And whenever potential factors are not known, qualitative inquiry is called upon to provide additional insight (Luthar & Brown, 2007; Rutter, 2006; Ungar, 2003). As Ungar has argued, qualitative methods can make a substantial contribution to the study of yet unknown and “unnamed protective processes relevant to the lived experience of research participants” (p. 85).

Although a qualitative approach is well suited for this study’s aims, it is important to note that this approach has several potential limitations. Two traditional criticisms of qualitative studies are that their findings are hard to generalize, and that they are too subjective, or biased by the researcher’s preconceived notions (Kvale, 1996; Marrow, 2005; Patton, 2002). Fortunately, several guidelines and recommendations for conducting good qualitative research have been developed in recent years (e.g., Creswell & Miller, 2000; Elliott et al., 1999; Marrow, 2005; Onwuegbuzie & Leech, 2007; Patton, 1999, 2002; Stake, 2006), which I implemented as much as possible in order to minimize these potential limitations.

With regard to generalizability of findings, the most relevant guideline is to situate the sample by describing the research participants and their life circumstances in sufficient detail that a reader would be able to judge to what extent the study’s findings might be relevant to the people and situations to which they wish to apply them (Elliott et al., 1999; Marrow, 2005; Stake, 1995, 2006).

The most relevant guideline to guard against subjectivity is to employ at least one of several credibility checks (Elliott et al., 1999). These procedures reduce systematic bias in the data
collection, analysis, and interpretation. The first group of these procedures, sometimes referred to as *triangulation*, involves checking data and/or findings against other perspectives and may include (a) analytic triangulation, such as member checking (i.e., providing participants with the interview transcripts and/or the final study report and asking them for their feedback as to the accuracy of their statements and the validity of the researcher’s interpretations of their intended meaning) and peer review (i.e., peer reviewing the study report for discrepancies, overstatements, or errors), and (b) theory triangulation (i.e., looking at the same data from alternative perspectives, allowing for understanding of how findings are affected by different theoretical assumptions; Patton, 1999, 2002; Stake, 1995, 2000).

The second group of procedures includes providing sufficient information in the study report against which the reader can judge the credibility of findings; they include (a) *detailed descriptions* and grounding in examples (e.g., inclusion of as many of first-person descriptions as possible and necessary to provide the grounds for interpretation) and (b) *researcher reflexivity* (also referred to as “bracketing” [e.g., Moustakas, 1994], “positionality” [Guba & Lincoln, 1981], the “researcher as instrument” [e.g., Guba & Lincoln, 1981; Marrow, 2005], and “owning the perspective” [Elliott et al., 1999]), which refers to the researchers’ statement in which they specify their assumptions, theoretical orientations, personal anticipations, experiences, values, interest and anything else that they believe may affect the research process including its findings, as well as the strategies they used to manage them.

### 5.2 Case Study Design

In this project, I use a case study design, or, more specifically, a combination of single and multiple case study designs. *Case studies* are particularly valued for their suitability in studying *unusual phenomena*, be they extraordinary achievements, experiences, or minds (Garmezy, 1982; Gruber & Wallace, 1999). For example, they have been used to study extraordinarily gifted and creative individuals (Gardner, 1997; Wallace & Gruber, 1989), individuals who accomplished extraordinary achievements under extreme conditions (Nasby & Read, 1997), as well as individuals with disabilities, neurological and mental disorders, and brain damage (Asperger, 1944/1991; Binswanger, 1958; Kanner, 1943; Luria, 1968, 1972; Sacks, 1987, 1995;
Singleton & Newport, 2004; Weiskrantz, 1986). In fact, case studies are invaluable in clinical psychology and psychiatry where they played a central role in the discovery and understanding of mental disorders (Kazdin, 1981). Moreover, case studies have been specifically recommended for research that aims to capture and understand complex phenomena in their real life context (H. A. Murray, 1938; Yin, 1994). Because one of the aims of this study is better understanding of life experiences in a real life context, a case study design seems natural.

Case studies are conducted either with one individual or with a small number of individuals, usually between 4 and 15 (Stake, 2006). The former studies are called single case studies and the latter multiple case studies. The choice of the type of the case study depends on the purpose of the study. Single case studies have been recommended for in-depth studies of individuals or issues. Good examples of this kind of study are Luria’s (1968, 1972) classic studies of individuals with brain injuries and Allport’s (1965) study of a set of letters of one individual. On the other hand, multiple case studies have been recommended and used by researchers interested in understanding what sets some individuals apart from others or how similar or different a small group of individuals is (McAdams & West, 1997; Stake, 2006; White, 1952). Kanner’s (1943) and Asperger’s (1944/1991) studies of autistic children are classic examples of this kind of study. More recently, multiple case studies have been employed in research on creativity (Gardner, 1997; Gruber & Wallace, 1999; Policastro & Gardner, 1999). As Policastro and Gardner have argued, a “careful study of the lives” through analysis of commonalities in life histories of creative people enables us to search for “principles, norms and regularities” (p. 214). Similarly, Gruber and Wallace believe that an analysis of the case histories of creative persons can reveal important insights about creativity through the identification of life events that foster particular kinds of development. More to the point of this study, this method has been used to help understand factors that contribute to both improvement and the lack of improvement in atypical development. For example, Reis, Neu, and McGuire (1997) studied factors that contributed to the high achievement of “twice exceptional learners”—that is, students with both high-abilities and learning disabilities. Likewise, Anderson and Felsenfeld (2003) explored factors that contributed to recovery from stuttering, while Kos (1991) looked at influences that contributed to the lack of improvement in a group of reading disabled students. As already mentioned, Hauser and colleagues (2006) used a multiple case study design to explore factors
that contributed to good life outcomes of four young individuals with serious emotional and behavioral difficulties. In this study, I use a similar design.

Both single and multiple case studies can be used for gaining a deeper understanding of the case/s and gaining insight into an issue (Miles & Huberman, 1994; Stake, 1995, 2006). Stake (1995, 2006) refers to the former as *intrinsic* case study, and to the latter as an *instrumental* case study. In this research I carry out both kinds of case studies. More specifically, I conduct an intrinsic single case study (where I explore in depth the data of one participant with the aim of better understanding him) and an instrumental multiple case study (where I explore the specific issues—outlined in the research questions—across all 8 participants with the aim at gaining insight into these issues). Such a mix of intrinsic and instrumental case studies is particularly recommended when there is an interest in both the individual (for which a person-oriented intrinsic case study is recommended) and the specific issues or variables (for which a cross-case instrumental study is recommended; Miles & Huberman, 1994). Because in this project I focus on both the persons and the variables, I combine these two designs.

6 Participants

Initially, I sought 10 participants with the following inclusion criteria: (a) formal diagnosis of *Autistic Disorder* without mental retardation (i.e., “high-functioning” autism) or *Asperger’s Disorder* made by a mental health professional using the *DSM-IV* diagnostic criteria (APA, 1994) and (b) age of more than 25 years. Initially, I also planned that half of the participants would meet the criteria for a “good” life outcome and half for the “not good” life outcome, where the good life outcome was defined as (a) living independently, (b) having a paying job, and (3) having social relationships outside original families—as is usually defined in the literature on autism.

However, I encountered significant difficulties recruiting participants that met these criteria. Although 11 individuals were recruited, the final sample consisted of only 8 participants. Two of the recruited individuals did not complete the interviews for personal reasons (a death in the family in one case, and a set of health-, job-, and family- related reasons in the other) whereas
one completed the interview but did not meet the inclusion criteria (no documents about
diagnosis or schooling were provided upon repeated requests). Half of the participants were
recruited through local organizations that provide services to autistic individuals (Autism
Ontario, Aspergers Society of Ontario, Geneva Centre for Autism) and an Internet support
network for autistic adults (Ontario Adult Autism Research and Support Network, OAARSN),
all of which posted flyers advertising the study on their websites and/or bulletin boards. Two
participants were recruited through a colleague (one of these did not complete the interview);
two were recruited through their personal websites; one during the Autism Ontario conference
(this participant did not provide required documents following the interview, as agreed, and was,
therefore, excluded from the data analysis), and one was referred by another participant (this
participant was not interviewed). All interviewed participants received financial compensation of
$25 per hour.

Of the 8 participants, 7 were males and 1 was female. Their ages ranged from 25 to 63. One
participant completed high school, 3 college, 1 the first year of university, and 3 had completed
university each earning one of a BA, MA, or Ph.D. degrees (see Table 1). Half of the participants
were diagnosed with Asperger’s Disorder, and one each with residual Asperger’s Disorder,
PDD, PDD-Autistic Disorder, and Atypical PDD. Five participants were diagnosed in adulthood
(see Table 2). Six were, or have been, on antidepressant medication (see Table 3). (For a
summary of this information, see Table 4.)

All participants were—more or less—well adjusted, and I was not able to divide them into
groups according to their life outcomes as initially envisioned: individuals doing well and
individuals not doing very well. Rather, the contrast group could only be said to consist of
participants doing less well than the others. A similar approach was taken by Hauser and his
colleagues (2006), who purposefully chose for their contrast group individuals not particularly
successful; they were classified as “doing about average” (p. 11) and described as “hanging in”
(p. 12). The same could be said for the participants in this study. Also, the designations “doing
well” and “doing less well” were relative with respect to time: the more successful individuals in
this study have not always been successful—but seemed to be doing better than just “hanging in”
and surviving (on their own judgment, and according to the three criteria accepted for this study)
for most of their adult life. By the same token, those classified as “doing about average” may
only be so classified at the present; and in fact they all seem to be on their way toward improving their current statuses. Indeed, as Masten and Powell (2003) noted with regard to resilient individuals, we should “not expect a resilient person, however defined at one point in time, to be doing well every minute of the day, under all imaginable circumstances, or in perpetuity” (p. 4).

To protect the participants’ confidentiality, their names as well as any other proper nouns they used in the interviews were replaced by pseudonyms. The participants selected their own pseudonyms.

Table 1 Demographic Information

<table>
<thead>
<tr>
<th>Par.</th>
<th>Age</th>
<th>Sex</th>
<th>Current Employment</th>
<th>Previous Employment</th>
<th>Education</th>
<th>Home</th>
<th>Marital status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pierre</td>
<td>46</td>
<td>M</td>
<td>Unemployed; volunteers</td>
<td>File clerk; P/T</td>
<td>Ph.D. History</td>
<td>With parents</td>
<td>Single</td>
</tr>
<tr>
<td>Mike</td>
<td>45</td>
<td>M</td>
<td>Office manager; F/T</td>
<td>N/A</td>
<td>B.A. Geography</td>
<td>Owns house</td>
<td>Married^{f}</td>
</tr>
<tr>
<td>Orville</td>
<td>63</td>
<td>M</td>
<td>Retired</td>
<td>Surveyor; electrician (self-employed)</td>
<td>1 year university</td>
<td>Owns house</td>
<td>Single</td>
</tr>
<tr>
<td>Sarah</td>
<td>25</td>
<td>F</td>
<td>Page; customer service representative; P/T</td>
<td>N/A^{d}</td>
<td>College</td>
<td>With parents</td>
<td>Single</td>
</tr>
<tr>
<td>Alan</td>
<td>31</td>
<td>M</td>
<td>Unemployed; volunteers</td>
<td>Technician</td>
<td>College</td>
<td>With parents</td>
<td>Single</td>
</tr>
<tr>
<td>Geoff</td>
<td>47</td>
<td>M</td>
<td>Unemployed; about to start</td>
<td>Office work</td>
<td>M.A. Sociology College</td>
<td>Rents apartment</td>
<td>Single</td>
</tr>
<tr>
<td>Howard</td>
<td>36</td>
<td>M</td>
<td>Mail clerk; F/T</td>
<td>N/A</td>
<td>College</td>
<td>Owns condo</td>
<td>Divorced</td>
</tr>
<tr>
<td>Jimmy</td>
<td>39</td>
<td>M</td>
<td>Unemployed; in school</td>
<td>Restaurant manager</td>
<td>High school^{f}</td>
<td>With parents</td>
<td>Single</td>
</tr>
</tbody>
</table>

Note. F/T = full time. P/T = part time. Par. = participant.

^{a}This changed by the end of the study to “Phone representative; F/T”

^{b}This changed by the end of the study to “Office work; tutoring; 3 P/T jobs.”

^{c}This changed by the end of the study to “Unemployed.”

^{d}This changed by the end of the study to “Page; customer service representative; P/T.”

^{e}This changed by the end of the study to “High school; some college education.”

^{f}This changed by the end of the study to “Separated.”
### Table 2 Psychiatric History

<table>
<thead>
<tr>
<th>Par.</th>
<th>Diagnosis</th>
<th>Age of diagnosis</th>
<th>Previous</th>
<th>Other diagnoses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pierre</td>
<td>AS</td>
<td>40</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Mike</td>
<td>AS</td>
<td>45</td>
<td>No</td>
<td>Learning Disability; Developmental Dyslexia&lt;sup&gt;a&lt;/sup&gt;; Delusional Disorder; ADD&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Orville</td>
<td>PDD / AD</td>
<td>50</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Sarah</td>
<td>AS</td>
<td>15</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Alan</td>
<td>PDD</td>
<td>20</td>
<td>No</td>
<td>Anxiety Disorder</td>
</tr>
<tr>
<td>Geoff</td>
<td>AS-residual</td>
<td>40</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Howard</td>
<td>Atypical PDD</td>
<td>12</td>
<td>Learning Disability</td>
<td>No</td>
</tr>
<tr>
<td>Jimmy</td>
<td>AS</td>
<td>39</td>
<td>Social Anxiety Disorder; Depression</td>
<td>No</td>
</tr>
</tbody>
</table>

<sup>a</sup>This changed by the end of the study to also include “Delusional Disorder; ADD.”

<sup>b</sup>This changed by the end of the study to “No.” Both of these diagnoses were disconfirmed.

### Table 3 Treatment History

<table>
<thead>
<tr>
<th>Par.</th>
<th>Psychological Current</th>
<th>Psychological Past</th>
<th>Pharmacological Current</th>
<th>Pharmacological Past</th>
<th>Educational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pierre</td>
<td>Individual psychotherapy</td>
<td>No</td>
<td>AD</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Mike</td>
<td>No</td>
<td>Individual psychotherapy</td>
<td>No</td>
<td>No</td>
<td>SE: Grades 1 &amp; 2: 1 to1; Grade 3 - High School: partial integration</td>
</tr>
<tr>
<td>Orville</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>AD</td>
<td>No</td>
</tr>
<tr>
<td>Sarah</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>SE: Grades 4 &amp; 5</td>
</tr>
<tr>
<td>Alan</td>
<td>Individual psychotherapy</td>
<td>Individual psychotherapy</td>
<td>AD</td>
<td>AD</td>
<td>No</td>
</tr>
<tr>
<td>Geoff</td>
<td>No</td>
<td>Individual psychotherapy</td>
<td>Individual psychotherapy</td>
<td>AD</td>
<td>AD</td>
</tr>
<tr>
<td>Howard</td>
<td>Individual psychotherapy</td>
<td>No</td>
<td>AD</td>
<td>AD</td>
<td>SE: Grades 3 &amp; 4</td>
</tr>
<tr>
<td>Jimmy</td>
<td>Individual psychotherapy</td>
<td>No</td>
<td>AD</td>
<td>AD</td>
<td>No</td>
</tr>
</tbody>
</table>

<sup>Note</sup>. AD = antidepressants; Par. = participant; SE = special education.
Table 4 Summary of Participant Information

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>( N )</td>
<td>8</td>
</tr>
<tr>
<td>Age range</td>
<td>25–63</td>
</tr>
<tr>
<td>Male-female ratio</td>
<td>7:1</td>
</tr>
<tr>
<td>Current diagnoses</td>
<td></td>
</tr>
<tr>
<td>AS</td>
<td>4</td>
</tr>
<tr>
<td>PDD</td>
<td>1</td>
</tr>
<tr>
<td>PDD / AD</td>
<td>1</td>
</tr>
<tr>
<td>Atypical PDD</td>
<td>1</td>
</tr>
<tr>
<td>AS-Residual</td>
<td>1</td>
</tr>
<tr>
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Note. AD = Autistic Disorder; AS = Asperger’s Disorder; PDD = Pervasive Developmental Disorder.

7 Data Sources

Two types of data sources were used in this study: (a) personal documents, and (b) interviews. They are described next.

7.1 Personal Documents
Participants were asked to provide a copy of the document containing their medical diagnosis of autism, at least one school record, and at least one piece of autobiographical writing. These documents were collected for the purpose of validating participants’ statements with regard to their diagnosis, education, and at least some of their retrospective autobiographical information.

7.2 Interviews

In this study, I used three types of interview: (a) a demographic information interview, (b) autobiographical interviews, and (c) follow-up phone and/or e-mail interviews. They are described next.

7.2.1 Demographic Information Interview

This interview included questions about birth date, gender, level of education, type of schooling (special, mainstream, or a combination), medical diagnoses, types of interventions received so far, employment status, SES, residential status, marital status, and family members (see Appendix A).

7.2.2 Autobiographical Interviews

A semi-structured interview procedure, or an interview guide (Patton, 2002), was used for this study. The interview guide had a list of questions to be explored but actual questions and probes varied across participants with the goal of achieving a more conversational as opposed to interrogational atmosphere. This technique was chosen for three reasons: First, it allowed participants to express their thoughts and feelings in their own words. This is particularly important in light of the little research done with autistic adults exploring their own perspective of themselves and their lives.

Second, it allowed the researcher to probe the participants’ answers to make sure that the participants understood the intended meaning of the questions and that the researcher understood
the intended meaning of the answers. That is, it allowed for the negotiation of meaning of questions and answers (Mishler, 1986). Probing for intended meaning can provide unique insight into participants’ unique lifeworlds. This feature is particularly important because it is well known that autistic individuals’ understanding and use of language is idiosyncratic (Asperger, 1944/1991). In fact, not probing for intended meaning can potentially lead to serious misunderstandings in both real life (Attwood, 1998) and research situations (Vuletic et al., 2005).

Third, participation in an interview can have a therapeutic and emancipatory aspect for its participants (Hutchinson, Wilson, & Wilson, 1994; Mishler, 1986; van Manen, 1997). It provides an opportunity to the interviewees to analyze, organize, and integrate their life experiences. Mishler has argued that the interview has the potential to empower the participants through the promotion of their insight into their own experiences and life situation: it can “empower respondents by facilitating their efforts to learn and act” (p. 141). Moreover, there is ample empirical evidence that suggests that reflecting on one’s life experiences can have positive effects on the health and well-being of those who engage in such activity (Frattaroli, 2006; Pennebaker & Seagal, 1999).

The autobiographical interview used in this study was piloted on one autistic adolescent and four nonautistic adults. These interviews lasted from approximately 2 hours with the autistic adolescent to approximately 3 hours with non-autistic adults. The interviews proceeded in a funneling fashion—first, I asked the most general questions, and after the participants answered, I proceeded to ask more specific questions. The autobiographical interview consisted of five general topic domains, each consisting of a number of sub-domains: (a) self-understanding, (b) autism, (c) present functioning and life satisfaction, (d) significant life experiences, and (e) future orientation (see Appendix B). Although the interview was specifically designed for the purpose of this study, many of its questions were adopted from or inspired by existing literature. In what follows, I briefly describe and provide background for the questions used in the interview.

7.2.2.1 Self-Understanding
The first section of the interview involved self-understanding. It included questions in three sub-domains: (a) self-definitions, (b) strengths and weaknesses, and (c) self-evaluations. (a) The first part of the interview focused on participants’ current self-conceptions. The main question of this part of the interview (What kind of person are you?) was adopted from Damon and Hart’s (1988) *Self-Understanding Interview*. (b) In the next segment of the interview, I asked the participants to identify their strengths and weaknesses, to provide justifications for their answers, and to give some examples of how they are using their strengths and how they compensate for their weaknesses. This line of questioning was inspired by Sternberg’s conceptions of *successful intelligence* (1997) and *personal navigation* (Sternberg & Spear-Swerling, 1998). (c) The questions in the next part of the interview explored participants’ self-evaluation. For example, following Damon and Hart (1988) and Harter (1985), the participants were asked to identify what they like the most and least about themselves and whether they like or dislike themselves most of the time.

### 7.2.2.2 Autism

The second area of inquiry dealt with issues specifically related to autism. In this part of the interview, I asked participants (a) how they got to be diagnosed with autism; (b) what it feels like to be autistic, (c) what meaning they made of their autism, (d) what their most significant difficulties stemming from autism are, and (e) what coping strategies they developed to deal with any difficulties they mentioned.

### 7.2.2.3 Life Satisfaction

The third part of the interview involved participants’ current life satisfaction. The questions explored participants’ satisfaction with their lives in general and with respect to some specific aspects, such as the quality of relations with others, environmental mastery, employment or school, and financial situation. Following Kilpatrick and Cantril (1960), I also asked participants to describe their ideal (or the best possible) and the worst possible life they could have, and asked them to evaluate their current position on the imagined ladder going from the worst possible life towards the best.
7.2.2.4 Meaning Making of Past Experiences

The fourth section of the interview focused on the participants’ past life experiences and included questions about their (a) most important life experiences, (b) important life decisions, (c) turning points, and (d) attempts at personal change.

**Significant life experiences.** The first section of this part of the interview dealt with participants’ significant life-experiences. The questions that were asked were based on McAdams’ identity-as-a-life-story (1990, 1993) and Ferrari’s (1999) identity-as-a-movie approaches to identity and J. A. Singer and Salovey’s (1993) conceptualization of self-defining memories. To explore participants’ life experiences and what they mean to them, I first asked them to think aloud about their lives and to identify life experiences they believe are most important for understanding how they became the persons they are now. To help them organize their memories, I suggested that it might be helpful to them to imagine that they, or somebody else, wanted to make a movie, or a documentary, about their lives and needed to find out which events from their lives would be the most important to include. I also handed them a piece of paper which had the arrow line on its left side representing their “lifeline” and labeled in ten-year intervals from 1 to 50 (see Appendix C) and suggested that it might be helpful to them to further label the lifeline by inserting the short descriptions (like those used for book chapters) of significant events from their lives. After they marked their lifelines, I asked the participants to review their lifelines and choose three events that they now believe had the most influence on becoming the persons they are now. Next, I asked them to provide more details about each of these events. In addition, I asked several questions about other potentially important life experiences in order to, as Allport (1942) suggested, “mak[e] certain that omissions shall be due to judgment and not to neglect” (p. 179). These questions were about the most disappointing and happiest moments of their lives, as well as significant people in their lives.

**Significant life decisions.** In this part of the interview, I started to explore the agentic aspects of participants’ lives. I first asked the participants to choose three decisions that they have made in their lives which they consider to be the most important. I then asked them to explain why they
chose these decisions and what impact they had on their lives. Following Holahan, Sears, and Cronbach (1995), I also asked them about any regrets they might have about these decisions. For example, I asked them which choices they would make differently if they had the opportunity to relive their lives.

**Turning points.** The questions from this section of the interview were intended to further explore participants’ intentional personal development. More specifically, I asked participants about any decisions they might have made which radically changed the course of their lives. The questions in this section were based on the notion of turning points as self-initiated radical changes in the developmental course (Bruner, 1991).

**Intentional personal change.** The final section dealing with past experiences also explored intentional personal development. Here, I asked the participants whether they have ever intentionally changed anything about themselves as persons. I also asked them about their beliefs on the possibility of such changes.

### 7.2.2.5 Future Orientation

The segment focusing on future orientation has been informed by the works of Allport (1937), Bandura (1977, 1989), Markus and Nurius (1986), Nurmi (1989), Oyserman and Markus, (1990) and Trommsdorff, Lamm, and Schmidt (1979). Data in this section were obtained through questions about (a) “future autobiography,” (b) projections for the future, (c) perceived control over the future, and (d) possible selves and worlds.

**“Future autobiography.”** In this section, I asked the participants to provide a description/short story of their possible future life as if they were telling a “future autobiography” or to describe scenes for the ending of a movie about themselves. They were asked to provide two endings, one each for “the best possible” and “the worst possible” futures. The probes included questions about their future relationships, jobs and other activities, as well as about how confident they felt about attaining the best possible life and avoiding the worst possible life.
**Five-year goals.** The next section dealt with participants’ goals over the next 5 years, the strategies for reaching them as well as for dealing with obstacles they may encounter.

**Perceived control over the future.** Drawing on Bandura’s notion of self-efficacy (1977, 1989), in this section of the interview, I probed participants’ beliefs about their perceived control over future (i.e., whether actualization of the particular future will depend more on them or on external circumstances, and how).

**Being a different person and living in a different world.** In the last part of the interview, I asked the participants several hypothetical questions about themselves and the world being different. For example, I asked them to choose the kind of person they would want to be, if that would be possible to do, and the world in which they would want to live, if they had the opportunity to choose. I also asked them to imagine what life would be like if they were not autistic, and to evaluate whether that would be better, worse, or the same to them and why.

At the end of the interview, the participants had a chance to think about the information they gave me and see whether there was anything they wanted to change or add.

### 7.2.3 Follow-Up Interviews

After the initial interviews, all participants were re-contacted by e-mail, and, in some cases, also by phone. During these contacts, I sought clarifying or missing information, as well as a brief update on their lives.

### 8 Procedure

#### 8.1 Data Collection

#### 8.1.1 Personal Documents
Only 2 participants provided personal documents of substantive value: one was a set of diaries kept over a 3-year period and another an autobiographical manuscript prepared for publication. Other participants provided poems and essays (which were published on the Internet), as well as links to some of their other postings on the Internet, such as photographs and discussion group entries.

**A note about the diary data.** The participant had kept diaries for about 6 years—from 2003 until the time of the interview. He made the first two as well as the last diary available for my review. I read all three diaries and made notes about issues relevant to the research questions of this study. However, a significant amount of writing was not legible. Therefore, I sought the participant’s clarification for entries that included his subjective evaluations of events (as opposed to his descriptions of facts) at two additional meetings. I used the diary data only for comparisons and contrasts with the interview data (that is, the diaries were not analyzed separately).

In the first two diaries, each page was devoted to one day (with only a few exceptions), but the pages were not necessarily filled. Usually five to seven entries were made per day. However, the last diary was written as a continuous series of entries; sometimes more than a page was devoted to a day, whereas other days had only two or three short entries that did not fill a page.

### 8.1.2 Interviews

Interviews were scheduled for two sessions of approximately 1 hour each. Interviews with all but one participant were conducted in two sessions; interviews with 1 participant were conducted in 4 sessions. The actual lengths of the sessions varied from 35 to 180 minutes. Interviews with the 6 participants were conducted in the classrooms or library group-study rooms of the University of Toronto. Interviews with 2 participants were conducted in meeting rooms of community centers in their towns. In all cases, the rooms were free of distractions.

Upon agreeing to participate, all participants were provided with consent forms (in all except two cases this was done ahead of the interview via e-mail). The consent form informed the
participants about the research protocol and issues related to the assurance of their protection as research subjects (e.g., confidentiality and the right to discontinue the interview process at any time). The consent form also asked participants for their permission to audiotape and transcribe the interviews be audiotaped and transcribed. It also informed them that all materials would be stored in a locked cabinet in my office. At the beginning of the first meeting, I reviewed the consent form with each participant and allowed them to ask questions before signing it. In all cases, I emphasized the fact that their participation is voluntary and that they could terminate their participation in the study at any time without consequences.

After they had signed the consent form, I gathered the medical and school documentation that the participants had brought with them, or discussed any issues associated with obtaining them. All interviews were audiotaped. Recording began after the introduction of the study and the review of the consent form.

All interviews proceeded in the same fashion. The interviews were semi-structured, which means that I selected the topics I wanted to cover in the interviews and developed a general interview protocol with questions and specific probes. However, my goal was not to ask exactly the same questions in exactly the same order. Rather, I tried to make the interview feel more like a conversation and when participants introduced topics “out of order,” I followed them and adjusted my questions and probes accordingly. I also listened to topics raised by participants that were not on my list. During interviews, I took minimal notes because I did not want participants to feel like they were interrogated. However, immediately after the interviews, I made notes about my observations, and impressions, as well as possible follow-up questions.

The general order of interviews was constant: The participants were first asked the questions from the demographic questionnaire and then from the autobiographical interview. The general order of interview questions was kept as constant as possible. The interview started with questions about the present, proceeded with the questions about the past, and concluded with questions about the future. The interviews were conducted in the tradition of clinical and research interviewing (e.g., Damon & Hart, 1988; Kvale, 1996; Sullivan, 1954).
After the first interview session with each participant, I listened to the audio-recording several times in order to prepare for the subsequent session and to get to understand the participants better. During listening, I made notes and formulated additional questions regarding anything that needed to be clarified. The second, or any other subsequent session, usually started with these clarifying questions.

Each participant was interviewed individually in a quiet room, as free of interference and distractions as possible. No participant indicated nor could I observe that they were disrupted by environmental stimuli (e.g., noise, light, smell, etc.) that could have interfered with their optimal participation in the study, and they all appeared fully focused on my questions and their answers.

At the beginning of the interview, the participants were also told that they should let me know when they needed a break. Several did so. I would also usually ask halfway through the session, as well as intermittently, if they needed a break. Most participants had a minimum of one break during each session.

8.2 Data Analysis and Interpretation

Data analysis is broadly based on a combination of procedures used in qualitative case and multiple case studies (Miles & Huberman, 1994; Stake, 1995), particularly those that use phenomenological (e.g., Davidson, 1994, 2003), interpretive phenomenological (J. A. Smith & Osborn, 2003), and narrative approaches (Hauser et al., 2006). Data analysis involved the following steps: transcribing, categorizing, and case and cross-case analyses. Next, I describe each step.

8.2.1 Transcribing

After the interviews were completed, they were transcribed verbatim from the audio-recordings. Although I transcribed most of the interviews myself, several interviews, either partially or wholly, were transcribed by two transcribers whom I previously trained in the general approach
to transcribing as well as in specific transcription conventions (see Appendix D). Both transcribers signed the confidentiality agreement prior to starting with transcriptions. After I received the interview transcriptions from them, I listened carefully to the recordings while reading their transcripts and made necessary corrections, additions, and editorial notes.

The completed transcriptions of each participant’s interview were then sent to that participant for review. Participants were invited to read the transcripts carefully and check for accuracy and to make any corrections and/or changes if they so desired. After receiving suggested changes from participants, the transcripts were corrected accordingly and sent back to participants for their final approval. The final set of transcribed interviews consists of approximately 1000 pages.

8.2.2 Categorizing Data

The second step in data analysis involved data categorization. I started with a list of analytical categories derived from the research questions. This list consisted of the following 9 categories: (a) intentional personal development, (b) self-understanding, (c) autism, (d) diagnosis, (e) social relationships, (f) life adjustment, (g) significant life experiences and influences, (h) future orientation, and (i) good life. During the categorization process, I developed additional analytical categories and sub-categories to allow for more detailed explorations of relevant psychological concepts. For example, within the self-understanding category, new subcategories included self-reflection, self-definition, self-evaluation, strengths and weaknesses, emotions, cognition, personality, and autobiographical memory.

Categorization of interview data was conducted along the lines described by Miles and Huberman (1994). The categorization started with the construction of summary tables in the form of participant-by-sub/category matrices. The next phase involved reading each participant’s transcript, and copying and pasting key words and phrases into the tables. The completed tables allowed quick data reviews both by category (vertically) and by participant (horizontally; see Table 3 for an example). Moreover, the quotes allowed a quick way of retrieving the relevant part of the interviews by entering the phrases as search terms. The interview material was also analyzed using content analysis based on procedures described by Miles and Huberman (1994);
for example, this procedure was used to analyze participants’ understanding of their emotional experiences.

8.2.3 Individual Profile Construction (Within-Case Analysis)

The original design for this study was a multiple case study. However, based on the amount, range, and uniqueness of information I obtained from one of the participants—the person who, in addition to participating in the interviews, provided his diaries for review—I decided to present a more detailed case study of this individual. In case studies, such change in research design is not only acceptable but desirable (Stake, 2006) as it reflects openness of the researcher to emerging issues that could not be planned in advance. In this case, I did not know about the participant’s diary-keeping practice. Given that, to the best of my knowledge, there are no studies in the literature on autism that explored diaries of autistic individuals, I considered it important to use the opportunity to explore this valuable source of information as deeply as I could.

The case study consists of three parts: two descriptive and one interpretative. Although descriptions and interpretations are often blended in contemporary qualitative research, some qualitative research methodologists (e.g., Marrow, 2005; Patton, 2002; Wolcott, 2001) recommend they be distinguished, as is usually done in clinical (e.g., Asperger, 1944/1991; Kanner, 1943, 1971) and life history research (e.g., Allport, 1965; White, 1952), and as I have done in my MA thesis (Vuletic et al., 2005). In the present research project, in an effort to find a balance between description and interpretation (or first- and third-person perspectives) in science (Ferrari & Vuletic, 2005; Vuletic & Ferrari, 2005), I take an approach that is similar to the one I used previously.

Separating descriptions from interpretations has two important advantages over the more common “blending” approach (i.e., approach where summaries of what participants said are provided in researchers’ words, and where participants’ words are used only to illustrate a specific point). First, the approach taken in the case study gives the research participants as full a voice as possible, which, in turn, gives them full ownership of their words. I use the concept of “voice” as Gilligan (1982) described it:
By voice I mean something like what people mean when they speak of the core of the self. . . . [Voice] is composed of breath and sound, words, rhythm, and language. And voice is a powerful psychological instrument and channel, connecting inner and outer worlds. (xvi)

Although Mishler (1986) has long argued that researchers’ summaries “do not adequately represent what is actually said” (p. 91), it is only more recently that the ethical aspect of this practice has also been questioned (Josselson, 1996a; Smythe & Murray, 2000). In fact, it is not uncommon for those who have participated in qualitative research to object to researchers’ accounts of them, saying that these accounts do not “feel” like them (Josselson, 1996b). Moreover, participants have often expressed feelings of having been betrayed by researchers by not being allowed to speak for themselves (Josselson, 1996a; Smythe & Murray, 2000) or of having their words “stolen” (Apter, 1996, p. 31). These and similar objections made by qualitative research participants have led Smythe and Murray (2000) to argue that ownership of participants’ narratives is a central ethical problem in narrative research, and, by extension, all qualitative research. For these reasons, and in light of the doubts expressed in the literature about autistic individuals’ ability to “present their own side of things” (Frith & Happé, 1999), giving autistic individuals full ownership of their words is particularly relevant. In fact, one of the aims of this project is to gather and present autistic individuals’ descriptions of their experiences.

The second advantage of this approach is that it avoids the often-raised criticism of qualitative research that it is not valid because it does not provide enough of a foundation on which to base its conclusions (Kvale, 1994; Mishler, 1986). As Mishler put it, “it is only through knowing what [the interviewees] say that we can begin to address the question of what they mean” (p. 51). The approach taken in the case study is a direct attempt to avoid this criticism by providing as much of the background data as possible, which makes the study transparent enough so that another researcher should be able to fully scrutinize the basis of the interpretations and conclusions. In addition, this approach allows the reader to, as Allport (1965) put it, “understand the drama—in his [sic] own way” (p. 157).

**Introductory description.** This section aims to situate the participant in a broader context and to give the reader a sense of the “range of people and situations” to which the study’s conclusions

might be relevant (Elliott et al., 1999, p. 228). The section provides a basic description of the participant and his life circumstances based on the information obtained from all three sources: the demographic questionnaire, the autobiographical interview, and the diaries. In keeping with the tradition of clinical studies, and in an attempt to aid the reader’s sense of the participant, in this part I also share my impressions and observations of this person: my first as well as general impressions of him, and my impressions about his general style of answering questions and level of comfort during the interview.

**Interview report.** The goal of this section is to let the participant speak for himself. As Gilligan (1982) put it, “the way people talk about their lives is of significance . . . the language they use and the connections they make reveal the world that they see and in which they act” (p. 2). However, presenting interview data is associated with a major challenge stemming from the possibility of selection bias. In order to minimize this threat, I made all efforts to follow the requirement of phenomenological research to “bracket” my assumptions (Moustakas, 1994; Patton, 2002; Wolcott, 2001) and present what the participant said (and occasionally did) regardless of whether it coincided with my expectations. As suggested by Patton, I gave all interview data equal value and consideration but included only what was “substantively significant” (p. 503) in the report. Yet, deciding what is “substantively significant” is not always straightforward.

I decided to exclude only (a) repetitive and (b) irrelevant information. Information was judged to be *repetitive* if it contained the same idea but differed in wording (i.e., if it did not have any additional meaning). However, a special note was made of the recurring topics. Information was deemed *irrelevant* if it was not related to any of the posed questions, that is, if it could not add anything to the analysis other than serve as an example of how the participant went on a tangent or avoided answering a question. However, if present, these tendencies would be noted as a general observation about the participant’s style of answering questions. Finally, to ensure that there was no selection bias in presenting the data, the participant was asked to review the draft of his profile and indicate whether there were any omissions or misrepresentations of what he said. Given the fact that he also had the transcript of his interviews, he was in a position to check what he said against what was included in the report. Unfortunately, although the participant reviewed
his interview transcript, he expressed his desire not to read the final report out of fear that he might be upset with what I could have written about him.

Because one of the main requirements for qualitative research is that it provide “thick” descriptions, which in addition to participants’ own words also include the context in which they appear (Creswell & Miller, 2000), in addition to the participant’s answers, I also provide my questions, if they were not evident from the section’s title or were part of an unrelated question. However, these questions were, most of the time, presented in very reduced form, similar to the approach used by others (e.g., Hauser et al., 2006).

For the most part, the interview report is structured around the research questions. In fact, one of my main roles in this section was to organize the participant’s responses so that any general patterns in responses would become clearer.

**Interpretative summary.** The main aim of this part is to bring the interview data to focus and into context by putting the segmented data into the context of the individual as a “whole” and the context of the relevant literature (Allport; 1965; L. Davidson, 1994, 2003). However, there are no clear rules or procedures of how to interpret the data. According to C. Taylor (1971/1979), interpretation is an “attempt to make clear, to make sense of an object of study” (p. 153), whereas Peshkin (2000) defines it as “an act of imagination and logic [which] entails perceiving importance, order, and form in what one is learning” (p. 9) and which involves processes such as selection, ordering, associating, and meaning making.

Interpretive procedures that I used include selecting issues relevant to a particular research question; noting contradictions and inconsistencies in the data, and then trying to reconcile them; comparing the interview data with diary data; comparing the participant’s descriptions with other first-person descriptions of autistic individuals from the literature; and providing links to research and theoretical literature.

When interpreting data, I put special emphasis on providing *multiple first- and third-person perspectives* on the same data. As Luria (1979) put it,
[science’s] main goal is to view an event from as many perspectives as possible. The eye of science does not probe “a thing,” an event isolated from other things or events. Its real object is to see and understand the way a thing or event relates to other things or events. (p. 177)

Many other philosophers (e.g., N. Goodman, 1978; Rabinow & Sullivan, 1979; Taylor, 1979), psychologists (e.g., Allport, 1942; Gergen, 1982; W. James, 1909), and qualitative methodologists and researchers (e.g., Guba, 1981; Guba & Lincoln, 1981; Patton, 2002) argued that in human sciences, considering multiple perspectives or interpretations—even parallel existence of opposing realities—is indispensable. For example, discussing the interpretation of personal documents, Allport wrote,

Seldom, if ever, do we find that the interpretation of the document is *compulsory* [italics in original]. Sometimes it is clearly forced or strained; but more often it seems to be merely *one of many* [italics in original] possible interpretations that could be imposed upon the material.

Any life, it seems, can be fitted into a variety of frames, and no way has been found to compel psychologists to let the case dictate its own proper frame. (p.142)

This position is taken to its extreme by Guba (1981) and Guba and Lincoln (1981) who argued that “social/behavioral phenomena exist chiefly in the minds of people, and there are as many realities as persons” (p. 77).

Providing multiple perspectives on the same data has important implications for both the readers and the participants. With regard to the readers, it puts them in a position to choose a perspective, or a combination of perspectives, that are most meaningful to them. As Allport (1965) put it, each reader must “consider the arguments, weight them, and render his own verdict” (p. 211) keeping in mind that, as Kaplan (1964) reminds us, every “interpretation is a hypothesis” (p. 32). In addition, stating at the outset that there are no right or wrong interpretations (see also N. Goodman, 1978; Vuletic et al., 2005)—or, to borrow from Rabinow and Sullivan (1979), “no privileged position, no absolute perspective, no final recounting” (p. 6)—but only interpretations that are more or less meaningful to the interpreter, also serves to invite the readers to come up with their own interpretations. Finally, as previously mentioned, providing multiple perspectives is specifically recommended for guarding against subjectivity of interpretations (Patton, 2002).
More important, multiple interpretations are more likely to be beneficial to the study participants. First, they may serve to ease the distress they might feel when reading unfavorable interpretations. Although sharing research results with participants is an ethical obligation of all researchers with human subjects (American Psychological Association, 2002), it is also a source of potential harm whenever individual, as opposed to aggregate, research results are provided (for discussions of this issue, see Bakan, 1996; Josselson, 1996a; Smythe & Murray, 2000; Yin, 1981). W. James (1902) recognized this possibility more than hundred years ago when he wrote,

> Probably a crab would be filled with a sense of personal outrage if it could hear us class it without ado or apology as a crustacean, and thus dispose of it. “I am no such thing,” it would say: “I am MYSELF, MYSELF alone.” (p. 9, original emphasis)

Likewise, Smythe and Murray (2000) more recently wrote about “the emotional impact of having one’s story reinterpreted and filtered through the lenses of social scientific categories” (p. 321). Given that researchers also have an obligation to minimize the risk for harm and maximize the potential for benefit to the participants, case study researchers are in a unique position where they must balance scientific honesty with protection from harm. In the absence of any specific guidelines as to how to approach this sensitive issue, I believe that providing both favorable and less favorable interpretations of the same data whenever possible may be one way to minimize a potential harm from reading single unfavorable interpretations.

Second, multiple interpretations also convey to the study participants the relative nature of all interpretations of human experience and development, which are necessarily socially constructed. They convey the idea that, as Maturana and Varela (1987/1992) put it, “Everything said is said by someone” (p. 26, emphasis added) and that “what he says is not said from anywhere” (Foucault, 1969/1972, p. 122) or at any time, but always from a particular standpoint at a particular historical time. In other words, what is said in human sciences always depends on the speaker’s values, interests, and beliefs, including those about the nature of scientific knowledge, as Foucault (1966/1970), J. Habermas (1968/1971), and others, remind us. As showed in the introductory part of this thesis, what is said about psychological phenomena usually changes in historical time (as well as geographic space; Grinker, 2007) and, as history
tells us, currently dominant interpretations are destined to become obsolete in the foreseeable future when new paradigms replace the current ones.

Multiple interpretations also make it more likely that the participants might find some benefits from research participation even if they experience some distress, which is particularly important in research with more vulnerable participants, such as individuals from clinical populations. Given the tendency of autism researchers to look for and propose single interpretations (best exemplified in the scientific discourse on “core deficits”), to ignore personal dimensions (i.e., aspects of individuals that are not part of “symptomatology”), and to pathologize anything outside the norm (Fenton & Krahn, 2009; Vuletic et al., 2005), providing multiple interpretations establishes a more balanced, if not humane, “epistemological space” (to borrow a term from Foucault, 1966/1970). I believe that this is achieved when autism is put in the context of individuals and their personal needs and norms—not just in the context of developmental, medical, or other social norms. As Deegan (1996), an academic who recovered from schizophrenia, remarked,

> Just as the generic, anatomical heart does not exist, neither does the schizophrenic or the multiple or the bipolar exist outside of a generic textbook. What exists, in the truly existential sense, is not an illness or disease. What exists is a human being and wisdom demands that we see and reverence this human being before all else. (p. 92)

For all these reasons, during the interpretive phase, I tried to imagine how the participant might feel when he reads my interpretations, and, to this end, I made them as tactful as I could. (I also stayed away from dehumanizing generalizations often used in academic literature on autism such as “impairments” and “mindblindness.”) In trying to balance scientific and personal harms and benefits, I decided to err on the side of scientific rather than personal. However, as others (e.g., Allport, 1965; Josselson, 1996a; Yin, 1981) noted, regardless of the effort, it may not always be possible to spare the other of hurt feelings, which is a realization that introduced a significant discomfort, if not “anguish” (as Josselson called it; p. 70) into this phase of the project. Like Allport, who commented on his feeling of discomfort when interpreting life and mind of Jenny Masterson (who, by the way, was not alive and thus not in a position to read his interpretations), I wished I could, “take refuge in vague generalizations” (p. x).
However, despite all these qualifications, I hope that the interpretive summary will yield some benefits to the person whose life I “put under the microscope.” As Thorne and McLean (2003) argued, “The personal past can take on new meanings when viewed from alternative perspectives” (p. 173). It is my hope that after reading my interpretative summary, the participant will think that he “liked having the chance to look at [him]self in a new way,” which is how he felt when he got diagnosed with Asperger’s disorder.

8.2.4 Group Profile Construction (Cross-Case Analyses)

The final analytical step involved the cross-case analyses, which were aided by previously-described summary tables, which allowed both (a) detection of patterns within each participant’s data and (b) comparisons among participants. Like the case study, the presentation of other participants also started with their Introductory Descriptions. However, instead of presenting full Interview Reports and Interpretive Summaries for each participant separately, as was done for the case study, interview data of all other participants and their interpretations were presented as part of the case study’s Interpretive Summaries, adhering, as much as possible, to the same general guidelines used in the case study. In other words, using the case study as the starting point, I compared other participants’ responses to each research question and within each analytical category. The final product of these analyses is presented as a group portrait built around the research questions where each participant is represented either as being similar or different from other participants with regard to a particular analytical category.

8.3 Researcher-As-Instrument Statement (Positionality Statement)

According to the methodological recommendations for conducting credible qualitative studies, here I frame my background, experience, and assumptions I believe to be relevant to how I carried out this research.

My academic background is in Clinical Psychology (BA & MA) and Human Development and Applied Psychology (MA). The psychological tradition that I most associate with is that of the
humanistic psychology of Maslow (1954, 1962) and K. Rogers (1961) whose core principles and aims I have adopted. Perhaps it is from this tradition that the seed of my belief came, that research on autism needs to include studies as much of autistic individuals’ strengths as of their weaknesses. In fact, I strongly believe that we need to identify both strengths and weaknesses; in order to help people learn to overcome their weaknesses, we need to understand the strengths they might use to develop compensating strategies (as Sternberg, 1997, has aptly argued). I also believe that the current overemphasis of mainstream science of autism on autistic individuals’ weaknesses (or, as they are usually referred to, deficits and dysfunctions) may, in fact, lead to the reduction of human potential and, further, pose a serious risk of harming people by diminishing their aspirations, or, to borrow from Hacking (1986a), by “chang[ing] the space of possibilities for personhood” (p. 229). Here also lies my abhorrence of researchers’ use of dehumanizing descriptors for human beings, such as mindblindness, “lack of self,” dysfunction, and deficit. In fact, I worry about the influence of such labels on autistic individuals who read the “scientific” representations of themselves in a way that Hacking (1995) refers to as the “looping effects of human kinds.” As I confront these concerns, my position is given clarity and support by the wise counsel of Szasz (1960):

The lure of positivism may be difficult to resist, but the student of man must resist it or fail as a humanist. For in behavioral science, the logic of physicalism is patently false: it neglects the differences between persons and things and the effects of language on each.

(p. 191)

The second important psychological tradition I am indebted to is a person-centered tradition (sometimes referred to as idiographic tradition; Allport, 1942) and personology of H. Murray (1938), as well as of Allport (1942, 1965), Rogers (1961), and White (1952). I have also been influenced by work of Lewin (1935, 1939), particularly his idea about “life-space,” as well as with Luria’s “romantic science” (1968, 1972). All these traditions contributed to my basic belief that human beings are complex creatures whose essences could not be grasped by knowing isolated pieces about them, a belief that profoundly influenced this research in all of its aspects.

For my developmentally-oriented thinking, I am indebted to two of my “developmentalists” professors, Ivan Ivic and Robbie Case. My thinking about human development was further
influenced by German *life-span psychology* (Baltes, Staudinger, & Lindenberger, 2006; Brandtstädter, 2006; Brandtstädter, et al., 1999).

As a student of *applied psychology*, I believe that psychological research should address “the pressing human problems” (Lerner, Fisher, & Weinberg, 2000, p. 11). As such, I also believe that psychological research should have an obligation to give something back to its *participants*. At the minimum, it should have an emancipatory function (i.e., provide them with the relevant information that could broaden their epistemological horizons). To this end, in this study, I try to incorporate information on issues raised by the participants that I believe might be of some use to them, to provide a bridge between research and the participants’ own lives.

I am also an avid reader of philosophy, sociology, anthropology, and life histories (biographies and autobiographies). This background and my continued interest in both clinical and non-clinical psychology provides me with a broad context that goes beyond the mainstream clinical perspective, which is relevant to all phases of this research, from formulation of research questions, to interview design, and data interpretation.

*My practitioner’s background* includes almost 3 decades of work with autistic children, adolescents, and young adults, as well as with individuals who are a part of their worlds, including their parents, grandparents, siblings, teachers, and friends. My work with them influenced the selection of my study topic and research questions, as well as specific interview questions. In my work, among other things, I facilitate the development of autistic individuals’ development of self-awareness and strongly believe in its importance for successful social adaptation. Although this belief may have influenced my data amylases and interpretations, I made all attempts to control for it by employing appropriate validity checks, which I previously described.

As a practitioner interested in understanding individuals, I have always found reading case histories, biographical, and autobiographical accounts more informative than quantitative studies aimed at supporting particular hypotheses. In fact, I read many of these accounts several times, each time discovering new human dimensions in them, which was not the case with any of the quantitative studies. Because this reading experience has provided me with a deeper understanding of autism than was possible from scientific literature, I have developed an interest
in further exploration of subjective experiences of autistic individuals, which I explore in this study.

My most relevant research background includes my already-mentioned MA study, which was a single case study of a twelve-year-old boy diagnosed with Asperger’s Disorder (Vuletic et al., 2005). This experience is relevant for this research in several respects. First, it provided me with a valuable experience in all aspects of qualitative research. More specifically, in the course of this study I conducted and analyzed semi-structured interviews with the main participant, his parents and grandparents, his best friend, and his former educational assistant. I also analyzed my casual conversations with the main participant as well as his autobiographical essays. Second, in this study, among other issues, I also explored the self-understanding of the main participant. To this end, I administered Damon and Hart’s (1988) Self-concept Questionnaire and Harter’s Self-perception Profile for Children (1985), which facilitated my deeper understanding of issues involved in self-understanding. Finally, the results of this study, as well as my experience with other autistic individuals, have contributed to my belief that self-awareness in autistic individuals is not necessarily diminished as usually presented in scientific literature, as reviewed above. This belief might have influenced my data analyses and interpretations. However, I made all attempts to minimize this possibility by employing appropriate validity checks as described above.

My relevant life background includes experiences of adjustment to school (in two cultures and at two life stages), work (in three countries), marriage, motherhood, family life, death of parents, war, being a refugee and an immigrant (involving being unemployed and not knowing the language of the country I was living in). This relative wealth of adjustment experiences puts me in a position to better understand the challenges associated with adjustment to different “worlds” and to be sensitive to their deep personal relevance. I believe that this experience facilitated my empathy with my participants, which has been recognized as a necessary ingredient of human understanding since Husserl (see L. Davidson, 1994).

As a person, I possess many autistic traits, such as high need for solitude, discomfort with chit chat, discontent with many “unnecessary” social conventions (with a tendency to avoid them whenever possible), tendency to say my honest opinion even when that is not in my best interest, often absence of spontaneous eye contact, high attention to detail, tendency to order and
systemize thing, and perfectionism. My father also possessed many of the same traits, perhaps to a greater extent. Like one participant in this study, my father had a deep connection with nature (as I do but to a lesser extent), and I believe this helped me empathize with this participant. Finally, I enjoy spending time with autistic individuals (of all ages) and find them uniquely interesting and valuable human beings whose existence greatly enriches human space. I have a deep respect for their way of thinking and being.

This combination of my academic, practical, research, and life experiences made me believe that intentional personal development may be an important aspect of successful adaptation of autistic individuals. Although this belief may be a source of a potential bias in this research, I remained fully aware of it throughout the research process and purposefully tried to minimize its influence by employing a number of validity checks as I described above, and which I summarize next.

8.4 Summary of Validity Procedures

In an attempt to minimize the potential methodological limitations of this study stemming from its qualitative nature, I employed 5 validity procedures common in qualitative research. They include:

1. Member checking. Member checking has been suggested as the single most important validity procedure in qualitative research (Guba, 1981; Stake, 2006). To this end, I provided all participants with both interview transcripts and the final study report and solicited their feedback as to the accuracy of their statements and my interpretations of them. Although their feedback was voluntary, all participants responded to this request. More specifically, 6 participants reviewed, commented on, and approved both the transcript and the report; 1 participant read, commented on, and approved the transcript only; and 1 did not read either but gave assent. Their comments were incorporated into the final study report.
2. *Peer review.* A colleague who both studies autism at the graduate level and is himself autistic served as a peer reviewer of the study report. I asked him to review the study report and provide me with his feedback with regard to any discrepancies, overstatements, or errors. His comments were also incorporated into the final study report.

3. *Detailed descriptions and grounding in examples.* In my study report, I provided a significant number of first-person descriptions. In fact, all interpretations were preceded by extensive relevant quotes from interview transcripts.

4. *Theory triangulation.* Each interpretation was accompanied by at least one alternative interpretation.

5. *Researcher-reflexivity.* I also provided a positionality statement in which I, to the best of my ability, outlined any relevant assumptions, experiences, and anticipations that could have played a role in this research. I employed procedures outlined above (1–4) to minimize my bias.
Chapter 3 Analysis and Interpretation

9 Portrait of Pierre and Sketches of Other Participants

9.1 Introductory Descriptions

*Note about quotes from participants interviews and documents.* Unless otherwise noted, all italics in quotes from participants’ interviews indicate participants’ emphases. All potentially identifying information about participants was changed to protect their confidentiality. Thus, none of the proper names in participants’ quotes are real names; to distinguish them from participants’ words, they are put in square brackets as is all other editorial material.

9.1.1 Pierre

Pierre is a 46-year-old man with a BA in mathematics, and an MA and a PhD in history. He lives with his parents in a large metropolitan city and is currently unemployed. Born into a university professor’s family, he is the youngest of five siblings. He was a precocious child who began reading at age three. A gifted student, he was allowed to skip Grade 3 and has spent most of his adult life studying: he completed his PhD studies when he was 39 years old. Since then he has been employed once, 2 years ago, for a period of six months. He does not have a romantic partner and has never one.

Pierre was diagnosed with Asperger syndrome at the age of 39. (He provided a note from his psychiatrist indicating a diagnosis but with no further details.) Since then, he sees a psychiatrist—usually once a month—who, according to Pierre, is helping him improve his social life. Prior to that, Pierre had received no psychiatric treatment. Although he is currently on antidepressants, he has not been formally diagnosed with depression.
Pierre lives his life day by day. His is a life devoid of the usual hurry, pressure and stress. He makes sure each day is interesting and enjoyable and a little different than the previous one—but not too much. His days revolve around arts, politics, comics, and oekaki puzzles. Pierre spends several hours every day reading (fiction and non-fiction books, comics, newspapers, Wikipedia and other Internet resources), watching DVDs, and going to the movies. He also sings in an amateur choir and an opera chorus and occasionally writes political essays for an online newspaper as well as his blog. Pierre also regularly takes continuing education courses—usually related to the arts, such as singing, dancing, drama, and creative writing. At election time, he volunteers at the local political riding. Occasionally, he is involved with other community projects. At home, he takes care of the garden (with his father) and occasionally bakes bread and prepares dinner for his family. Pierre has several casual friends with whom he occasionally discusses the arts, politics, and other topics, watches movies, visits places, and has dinner. He also likes to travel and has traveled within North America as well as Europe and Asia.

Pierre came to the first meeting in a somewhat old-fashioned outfit—which included an overworn hat—and with two books in his hands, one, a biography, which he was reading while waiting for me; the other, a book of oekaki puzzles. Although he looked at me when we met, he rarely, if ever, looked at me again. He walked in short strides, and appeared to have an unusual breathing pattern, which gave his speech an unusual rhythm. During the interviews, Pierre got tired more quickly than the other participants did. Whereas all other participants needed two sessions to conclude the interview (some of which were much longer than Pierre’s), the interview with Pierre took four sessions. During our third interview, Pierre opted to stop after 35 minutes and continue another time, adding that “answering questions can get a bit tiring.” (The longest of the four interviews was 1 hour 5 minutes—which was the duration of the shortest interview of all of the other participants, which ranged from 1 hour 5 minutes to 3 hours 6 minutes and averaged 1 hour 40 minutes.

Pierre’s emotional reactions to remembering some unpleasant events were also more intense than those of other participants—sometimes even scary. For example, he still experiences extreme levels of anger about events that happened over 30 years ago. Some of these events are still so painful that he refrained from even talking about them. While talking about emotional experiences, Pierre’s facial expressions changed quite a bit and he also made many hand
gestures—the rest of the time, his expressions did not change much nor did he make many hand gestures.

Pierre’s answering style was unique, which, at times, gave the impression that he was less than enthusiastic about the interview. For example, most of the time his answers were very short, and I often needed to follow up on them with requests for elaboration. He also replied to many questions with, “I cannot think of anything at the moment” and “I don’t know. I’d have to think about that,” so that I needed to revisit some questions several times. Moreover, many of his answers also included words and expressions of uncertainty such as *maybe, I guess, I suppose,* and *it’s possible.* On the other hand, Pierre was also the most entertaining participant: he recited poetry and included several short descriptions of books and films in his answers. He also laced some of his answers with humor, and, on our way out of the interview room, sang operatic arias. In general, Pierre left me with an impression of a pleasant, thoughtful, and interesting person with excellent conversational skills (except in matters related to his negative life experiences).

As already mentioned, Pierre was the only participant who kept diaries and was willing to share them with me. After I expressed my interest in seeing one of his diaries, Pierre offered and gave me diaries he had kept over 3 years. Moreover, Pierre was also willing to meet with me at two additional times to provide clarifications for the entries in which I was interested (which contained his subjective evaluations of events) and which I found partly illegible. Because Pierre was also willing to meet with me to discuss the interview transcript and to clarify some of his answers, I got to know Pierre much better than the other participants. Moreover, Pierre invited me to some of his choir and chorus performances, two of which I attended, so I got to know him in the real world, as well as to briefly meet his parents. Both of these experiences were extremely important for my fuller understanding of Pierre, and they, in many ways, changed my initial views of him based on the interviews and the diaries.

9.1.2 Other Participants

Like Pierre, all other participants provided documents from mental health professionals that confirmed their diagnoses with autism. Four participants were diagnosed at an institution renowned
for its expertise in diagnosing autistic individuals. The other 3 participants were diagnosed by psychiatrists or psychologists according to the *DSM-IV* criteria.

Next, I introduce the other participants in the order in which I interviewed them.

### 9.1.2.1 Mike

Mike is a 45-year-old man with a BA in geography who works as an office manager for the army. He has been married for 19 years, and he and his family, which also includes two children—one autistic, the other with a learning disability and ADD—live in their house in a small city. Mike’s spousal relationship has been strained since the birth of his autistic son. However, he has good relationships with his parents and his siblings, although he does not see them very often. Mike also maintains good professional relationships with his coworkers and sometimes socializes with his next-door neighbor. However, he does not have any close personal friends. Most recently, he started socializing with people who have similar interests through one virtual and one regular organization. Mike’s main interest is in paranormal phenomena, which he investigates with a national organization and publishes articles about his investigations on the Internet. In his free time, Mike also volunteers for local charitable organizations.

Following in his father’s footsteps, Mike entered the army after high-school. Before that, he was educated either in special education classes, including one-on-one settings in Grades 1 and 2, or in regular classes with withdrawal assistance for some of the courses, usually math and English. Mike moved to Ontario from Quebec where he had spoken French, just before starting kindergarten. He found it hard to adapt to the new environment, which his parents attributed to the language barrier. Because Mike “didn’t fit in” in kindergarten, the kindergarten staff wrote a special report about him saying that Mike “[did] not participate in group activities,” “[did] not seek [the] opportunity to do things with other children,” and “isolate[ed] [him]self from other children.” (Other observations included, “slight speech defect,” “seems to be full of fears,” “both fine and gross motor skills somewhat deficient,” and “easily distracted.”) Mike was then referred for assessment to the renowned pediatric hospital, where, at age six, he underwent extensive testing.
The psychiatrist’s report, which includes observations such as “rather critically detached from other people” and “[emotionally delayed] apparently due to an overly dependent relationship to parents,” concluded with the diagnosis of Learning Disability and Developmental Dyslexia. As an adult, Mike was assessed again and diagnosed with a Delusional Disorder. It was only after his own research of the literature related to his problems, which led him to seek out autism experts, that he was diagnosed with Asperger’s Disorder at age forty-five—only months before the interview. (Mike brought two diagnostic reports to the interview confirming his diagnosis of Asperger Syndrome: one by a psychiatrist and the other by a psychologist with an expertise in autism.) Most recently, after I interviewed Mike, his diagnosis of Delusional Disorder was formally changed to Asperger Syndrome. Although Mike received no special psychiatric treatment prior to the diagnosis of delusional disorder, he subsequently had about twenty sessions of Cognitive Behavioral Therapy and has been seeing a psychiatrist approximately every three weeks.

Although at the beginning of the interview Mike appeared somewhat tense, he later seemed more relaxed and occasionally smiled, chuckled, and made funny remarks. He was very responsive and eager to talk. His replies were rather swift, giving the impression that he had already thought about the issues I was asking him about, and his answers were very comprehensive. He also made several attempts to make the interview more conversational. For example, he asked me several questions, such as about my native language, the correct pronunciation of my last name, and my opinion about one of the issues he raised. He also often made eye contact. His tone noticeably changed when he talked about emotional experiences, both positive and negative. He appeared particularly emotional when talking about what he perceives as a “misdiagnosis” of Delusional Disorder as well as when talking about his negative life experiences, past and current. When talking about negative experiences, Mike often tapped on the table as if highlighting his words. Mike talked much more about his feeling of social isolation than did most other participants. In contrast to the other participants, he also made frequent references to hope, such as “I always had hope” and “I work a lot on hope.” In general, Mike left an impression of a pleasant, interesting, and caring person eager to talk to other people.
Although Mike brought a folder with a number of medical documents to the first interview, from which he read to me, as well as let me review them, he did not provide any autobiographical material. However, during the interview he urged me to read his articles on the Internet about his investigations of paranormal phenomena, which I did, and this provided me with an additional perspective on him. In addition to the main interview, Mike also provided some additional information in a follow-up phone interview. During this interview, I learned that soon after our main interviews, he and his wife separated.

9.1.2.2 Orville

Orville is a retired 63-year-old self-educated electrician who lives alone in his own house in a small town. He was employed for 25 years, 7 as a land surveyor doing both field and office work and another 18 as a self-educated, self-employed, licensed electrician. He retired at age 50. He recently went back to school and completed the first year of university in transportation engineering technology. (He discontinued his studies due to financial difficulties.) Orville has several friends, and although he does not have a romantic partner at the moment, nor was he ever married, he had one romantic, mostly long distance, relationship that lasted for about 5 years. Both of his parents are dead; however, he has four siblings and has a good relationship with his oldest sister who lives in another town. Orville has a life-long interest in trains and nature. His other, more recent, interests include landscape photography and computer graphic design. He occasionally writes poetry and publishes it on the Internet. He regards the development of a now well-established nature trail that he planned and organized the accomplishment of which he is most proud.

In school, Orville always attended regular classes but had a difficult time adapting to peer groups. Although he was sent for psychiatric and neurological assessments twice during his schooling, he was not given any definitive diagnoses at those times. His “psychiatric history,” taken from his latest psychiatric assessment, includes the following observations: At age 12: “normal intelligence, poor abstract reasoning with regard to social interactions, and a question of prodromal schizophrenia (because of flat affect, autistic features, and hypersensitivity to auditory stimulation).” At that time, it was concluded that Orville’s “[social] difficulties did not respond
to basic skill teaching, were not accompanied by anxiety, but were associated with poor abstract reasoning regarding social interactions.” According to the same document, he was in psychotherapy several times: at age 23, “for ‘personality difficulties’”; at age 45, “for ‘ventilation’ of frustration about business problems”; and at age 47, “for anxiety about financial problems.” At 47, he was assessed twice. The first time, it was noted that he “had poor insight into relationships,” whereas the second time, it was reported that he presented diagnostic difficulties and was passed from one diagnostic team to another for over a year. The final conclusion was that he was not psychotic, did not have any anxiety disorder, likely had a past episode of depression, but primarily had difficulties from a “personality disorder”, (trait vs. state feature) which could not be specified but had schizoid, avoidant and paranoid features.

It was only after his own independent research, at age 50—which led Orville, first, to believe that he might be autistic and, second, to seek an assessment in an institution renowned for its expertise in diagnosing autistic individuals—that he was formally diagnosed with Pervasive Developmental Disorder with the “impression” that he “fit[s] more with the classic (Kanner’s) type” than with Asperger’s. (All background information presented in this section is taken from this psychiatrist’s report.) At the time of the interview, Orville was not in psychotherapy nor was he on any medications.

During the interview, Orville appeared relaxed and very eager to talk about himself and his life. His interview was the longest (6 hours), and I had the impression that he could talk forever without getting tired. For example, after talking for over 2 hours during our second meeting, when I asked him whether he was feeling tired, he replied, “No, I’m not tired. I don’t seem to get tired of these things.” Orville’s eye contact was not noticeably absent, and although he mentioned his “bad habit” of having restless fingers and biting his nails (which he showed me to support his statement), he never bit his nails during the interview nor were his fingers noticeably restless.

Orville’s voice did not vary much with the change of topic from negative to positive experiences and vice versa. He talked as if he were afraid that there would not be enough time to say everything he wanted to say. For example, he would often start answering the question before I finished it. Moreover, when talking, he did not make pauses at the end of sentences but rather at
the end of his breath, which, together with his tendency to swallow parts of words, or even whole words, added to the hurriedness of his speech—as if his thoughts raced faster than he was able to say them. His answers were always long and elaborated, if not overly elaborated. For example, many of his replies were longer than a minute (with many being between 2 and 4 minutes long—some even longer), compared to other participants who only occasionally took over 1 minute to reply. At times, his style resembled a theoretical discussion or lecturing. He sometimes also made somewhat irrelevant comments and repeated his ideas, views, or observations. He often disregarded both my verbal and nonverbal attempts at suggesting that he already answered the question in a sufficient detail, which sometimes gave the impression that he was engaged in a monologue. Orville’s answering style was also characterized by rhetorical questions and quotes from his conversations with others (sometimes imaginary, where he would say things he believes others would say). Orville sometimes compared himself to others who had different views from his in a somewhat arrogant manner, accompanying many of his remarks with a characteristic half-laugh. Nevertheless, for the most part, he was very respectful of others. In general, Orville left me with an impression of a very thoughtful person who had a special sensitivity for his natural environment.

In addition to the copy of his latest psychiatric report, Orville also e-mailed me one of his poems and provided me with links to websites where his photographs were posted and to Internet discussion groups on autism in which he used to participate, all of which provided me with an opportunity to understand Orville and his views better. (Because his poem has been published on the Internet, in order to protect Orville’s anonymity, I will not consider it in this thesis. However, it is important to note that the poem represents Orville’s reaction to one of the world’s biggest natural disasters in history. For the most part, the poem deals with his feelings of sympathy towards the victims.) After the main interviews, Orville provided some additional information about himself in subsequent phone conversations and e-mails. It was during this contact that he informed me that, after the initial interview, he had become involved in a romantic relationship that had already lasted for several months.

9.1.2.3 Sarah
Sarah, twenty-five, is the only female participant in this study. She lives with her parents and her younger brother in a suburb of a large metropolitan city. Sarah holds two college diplomas—in accounting and library science—and two part-time jobs: as a page in a library and as a customer service representative in a video store (where she has been working for the past 6 years). She has several friends and has never had a romantic relationship. Sarah has a life-long passion for music and sings every week with a church choir.

Sarah was diagnosed with *Asperger’s Disorder* at age 15. She was diagnosed by a psychiatrist at an institution specializing in diagnosing autistic individuals. The psychiatric report includes Sarah’s history of motor mannerisms (e.g., flapping her arms, rubbing her hands together “really fast,” and swinging her head from side to side when walking and bobbing it when excited). Sarah’s difficulties with eye contact and adapting to change were also noted, as well as several of her rituals and obsessions involving, for example, talking to herself, taking off her glasses, and always placing her books in the same order on the bookshelf and correcting the order if somebody changed it. The report also mentioned Sarah’s difficulties with establishing friendships, being “teased and called names” (which made her feel frustrated and sad), and social anxiety. According to the report, Sarah worried “about interfacing with other children,” was “get[ting] butterflies” when trying to talk to them, did not know what to say, and worried that she will be rejected “or that she will be embarrassed.”

Except for the 2 years when she attended special education classes—Grades 5 and 6—she was educated in the mainstream classrooms but had received “core resource help” since Grade 3. In college, she was allowed extra time for tests and exams. During her schooling, she never received any special treatment for her social difficulties, which she described as having trouble making friends. However, after being diagnosed, she attended several social support groups organized by local organizations that specialized in working with autistic individuals.

Sarah came to the first interview with her mother (who left after we met and did not wait for the interview to end). Although Sarah made occasional eye contact, most of the time, she either kept her eyes closed or looked downwards. She occasionally smiled and her tone was pleasant. Her voice was delicate but gained in force when she talked about her talents and accomplishments, such as her audition for the music academy, her subsequent acceptance, and the accompanying
feeling of pride. When asked factual questions (about her friends, school, or jobs), she would answer immediately, without any hesitation. This was also true for some of the questions that required reflection, sometimes giving an impression of learned answers. On the other hand, usually when asked more atypical questions, such as what she liked most or least about herself and what being autistic means to her, she would take very long pauses before answering, sometimes longer than half a minute. During these pauses she often did not use any pause fillers, which sometimes made the silence feel awkward, prompting me to ask her whether she understood the questions. With several exceptions, she always answered yes. However, at least several of her answers suggest that her understanding of these questions was different than that of the other participants (which I discuss later).

The interview with Sarah was characterized by her rather short answers. Her initial response to many questions was often a simple yes or no, but when asked to say more, except for a couple of instances, she had no difficulty providing more detailed answers, although, compared to other participants, they were still the least elaborate. Consequently, her interview was the shortest—it was completed in approximately 2½ hours. On the other hand, some of her answers were the most precise. When asked questions involving time estimation, she usually replied giving the month and the year. For example, when asked how long she knew her current friends, she gave the exact month and year when she met them. Her use of some words and phrases, such as “normal life,” “like everybody else,” and “happy,” was also somewhat conspicuous, both because they were mentioned relatively often and because they were relatively absent in the interviews of other participants. For example, she used the word happy 11 times to refer to herself, compared to Pierre and Orville who never used it (contrastingly, Pierre used the word unhappy 4 times). Sarah’s interview was also memorable for her very positive attitude about everything we talked about.

In addition to the psychiatric report, Sarah also provide some additional information in two follow-up e-mails, from which I learned that soon after the main interviews, she found full-time employment in a call center and was still working there the last time I contacted her, more than a year after the interview.
9.1.2.4 Alan

Alan is a thirty-one-year-old single man who lives with his parents in a large metropolitan city. He possesses a college diploma obtained in a Special Needs Program focusing on basic academics and independent living. Although Alan worked once as a technician at the computer warehouse for about 5 months, he is currently unemployed. Instead, he volunteers for a local non-profit organization. He also takes part in drama performances with an amateur group. Although Alan has several casual friends, he does not have any close friends or a romantic relationship, nor did he ever have any. However, he seems to have good relationships with his parents, his brother and his family, and with his aunt. Alan has a keen interest in movies, TV shows, music, hockey, clowns, and celebrity lives.

Alan attended both special and regular classes. According to the psychiatric diagnostic report, which summarized his educational and psychiatric history, Alan was once “asked to leave [a private school] because of violent behaviour, dreamy states, etc.” As a child, he saw many mental health professionals but never obtained any definitive diagnosis until he was diagnosed with Pervasive Developmental Disorder when he was 20 years old. At that time, the diagnosing psychiatrist noted that “at 4 years of age, he had many signs and symptoms characteristic of a high functioning child with pervasive developmental disorder.” Alan’s parents sought this assessment (with one of the world’s leading experts on autism) after they read about autism and felt that it “fits many of [Alan’s] characteristics,” such as social isolation, difficulties with change and need for routine, and a restricted range of interests that included TV, video games, and news. At that time, Alan also obtained a diagnosis of Anxiety Disorder. The same document states that “behind the aggressive behaviour, there does seem to be mounting anxiety . . . . This he finds very difficult to control and becomes aggressive and violent as a way of letting off the anxiety.” Alan’s occasional violent outbursts continued into adulthood, with some resulting in police involvement and even arrests.11

11 It should be noted that 2 other participants also mentioned encounters with the police. Orville described an incident in which he was accused of threatening someone’s life and Jimmy, whom I introduce later, mentioned several drinking and driving incidents.
Before the interview, I got to know Alan in an informal, 45-minute conversation at a coffee shop near the interview location. This was a place he visits often, and he suggested we meet there. Although he rarely, if ever, smiled, Alan did not appear anxious and had relatively good eye contact. He seemed to enjoy talking about topics which touched his interests such as movies, clowns, noses, Halloween costumes, his upcoming drama performance, and the country of his parents’ origin, which he recently visited. It seemed that he could talk about these topics for a long time. Alan sipped his tea slowly and preferred to finish drinking it at the shop, ignoring my repeated suggestions of getting going soon. Another memorable aspect associated with this part of our meeting occurred while we were exiting the coffee shop. Alan stopped to say something to people sitting at one of the tables. Assuming that he knew them, I waited for him outside. However, he later told me that he stopped because two of the girls at that table reminded him of two actresses, and he just wanted to tell them that. He said the girls thanked him.

During the interview, just as during the getting-to-know phase, Alan rarely, if ever, smiled or chuckled. Both his demeanor and conversation style were very serious. He never attempted to make a joke. His voice was somewhat loud and forceful, and his speech was rather fast, which sometimes made his words unrecognizable. His intonation was also unusual in that he often emphasized particular words by making them unusually longer (e.g., d-e-e-tails, magaz-i-i-i-ines). Alan’s vocabulary was quite sophisticated, and he seemed to get special pleasure from pronouncing some words, such as “crescendo,” “anarchy,” and “grotesque.” Although he occasionally used hand gestures, his voice and facial expressions did not change much with topic changes.

Alan’s answering style was rather formal and pedantic. He rarely used any jargon and instead preferred to start his answers with “Yes, that’s right,” and similar formal replies, in contrast to all other participants—none of whom ever replied with that’s right, which Alan used 98 times. Alan also often finished his answers with a closing yes. His answers often included references to movies, TV shows, books, magazines, and popular songs, which he either mentioned, summarized, or attempted to summarize. In two instances, he quoted lines from popular songs. He also mentioned several characters from books and movies and many actors and singers. Although all these references were appropriate and would make a typical conversation interesting, they sometimes tended to take Alan away from the points he wanted to make. In
several instances, I also needed to remind him that I was more interested in his life than in movies; in most of these instances, he responded by going back to his life. On several occasions, Alan also attempted to engage me in a conversation. For example, he would say, “You ever watch those shows?” “You know the story of doctor Jekyll and mister Hyde?” or “You know what [it] means, tit for tat?”

Alan’s interview was also memorable for his many references to what he should not do (e.g., “try not to get carried away”; “not talk about things which are inappropriate, or disgusting, or crazy things”; “not to go to extremes”; “trying to not to go to details, not to obsess about details about things”). It was also characterized by his use of consecutive descriptors with similar meanings when talking about violence (e.g., “hitting [. . .], smashing, wrecking”; and “pummel me, beat the living daylights out of me”).

In contrast to other participants who did not talk much about their “obsessions,” Alan spent a lot of his interview time talking about his need to do certain things in a particular way (e.g., put his chewing gum out at a particular time) or to engage in certain activities (e.g., count his steps and buy celebrity magazines). He also both talked about and demonstrated his preoccupations with dark sides of life (“the world is going crazy with the war on terror”) and his tendency to go into too many details in a conversation.

Nevertheless, as Alan showed me outside the scripted interview environment, he is a good conversationalist and his extensive knowledge of film, music, celebrity lives, and other areas make him an interesting person to be with. Alan was also very polite. For example, he apologized for his appearance not being up to his own standards (“Sorry, I didn’t have time to shave earlier today, my beard grows so fast”), although, if he did not tell me, I would not have noticed it.

In addition to the already-mentioned sources of information about Alan, he also provided some additional information about himself in one e-mail and one phone follow-up interview. At the time of that interview, more than a year after the initial interviews, Alan reported that he was involved in a job training program, which he hoped would lead to employment.
9.1.2.5 Geoff

Geoff is a 47-year-old single man who looks much younger than his age. He holds a Masters degree in Sociology and has 14 years of work experience in various office jobs as well as note taking, close captioning, and other odd jobs, but who has been unemployed for the last 5 years. However, at the time of the interview, he had just obtained employment and was about to start working the day after the interview. Geoff currently lives alone in a co-op apartment in a large metropolitan city. Although Geoff had been married for 8 years, he did not have a romantic partner at the time of the interview. However, he had several casual friends and had a good, although not particularly close, relationship with his older brother. (Both of his parents were dead.) One of Geoff’s main interests is music. In addition to always liking listening to music, when he was younger, he also played drums in a band, with which he had recorded several CDs. He recently also recorded music in his apartment. Geoff’s second major interest is creative writing, and he aspires to become a professional writer. He has just finished writing his autobiography and is currently pursuing a publisher. He also likes to travel—and has traveled across Canada and oversees—as well as to take subway rides. He has a life-long interest in maps—subway maps in particular. He also likes exploring the city by bicycle, and going to baseball games.

During his schooling, Geoff always attended regular classes and was never referred for an assessment despite having social difficulties, which he described as not fitting in and being bullied. He started seeking psychiatric help, primarily for his depression and anxiety, in his early twenties. Although he had many years of psychotherapy, and in his early twenties was also on antidepressants, Geoff was not formally diagnosed with any psychiatric disorder until age 40, when he received a diagnosis of “residual type of Asperger’s Disorder” after he diagnosed himself as being autistic based on the information he found on the Internet. Geoff was diagnosed

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12 It is interesting that DSM-IV and DSM-IV-TR do not contain the diagnostic label for residual states of autism, as was the case with DSM-III, when the diagnosis “residual autism” was a separate diagnostic category. However, the current manuals do contain a provision that adults whose symptoms in childhood met the full criteria for any disorder, but at the time of assessment present “with an attenuated or residual form, the In Partial Remission specifier may be indicated” (APA, 2000, p. 39). However, the diagnosis “residual autism” is still commonly used both in practice as well as in the literature (see for example, Piven et al., 1996) although it has been argued that, at least in case of autism, this specifier has an inadequate connotation that autism had been outgrown, which is usually not the case (Piven et al., 1996; Volkmar & Lord, 1998).
by a psychiatrist at an institution renowned for diagnosing autistic individuals. According to the psychiatric report, Geoff came to the conclusion that he might be autistic based on

his fascination with maps and train and bus schedules, difficulties understanding social context, and difficulties socially, particularly with respect to dating individuals of the opposite sex, which [...] creates a lot of anxiety [...] and difficulty [...] making friends.

During the interview, Geoff appeared relaxed. He smiled, chuckled, and laughed when appropriate, and his facial expressions were appropriate to the context. His eye contact was relatively good, and he also occasionally made hand gestures. His voice was modulated according to the mood of his topic. Geoff was very responsive to all questions and only once responded with “I don’t know.” Nevertheless, after a prompt, he answered that question, too. Although his interview was second longest, his answers were measured for the interview situation, and the length of his interview should be attributed to his attempts to answer all of the questions as well as he possibly could. He clearly enjoyed talking about his involvement with music and writing. In contrast to the other participants, Geoff was the only one who talked about his spirituality, which it is an important aspect of his life, as well as about his sexuality, with which he has some unresolved issues. He was also the only participant who spontaneously talked about alcoholism in his family, which he considered a contributing factor to some of his psychological difficulties. (According to Geoff, his mother died of alcoholism and his father “drank a lot too.”) In general, Geoff left me with an impression of a pleasant, kind, and thoughtful person.

In addition to the interviews, Geoff also provided me with his autobiographical manuscript, from which I learned more about some of the events Geoff already described during the interviews, as well as about some events that he did not mention. All information contained in this manuscript was consistent with the information Geoff provided in the interviews. This manuscript also showcases Geoff’s excellent writing skills, as well as attention to detail. Finally, Geoff also provided some additional information in four follow-up e-mails. The last time I contacted Geoff, more than a year after the interview, he had “2 1/2 part-time jobs: captioning/video description, courier, and tutoring a Grade 10 student in English.”
9.1.2.6 Howard

Howard is a thirty-six-year-old single man who looks much younger than his age. He holds a college diploma in accounting but has been employed for 11 years as a mail clerk. He lives alone in his own apartment in a large metropolitan city. Howard takes great pride in having a job and owning his place of residence. He has several casual friends from two groups to which he belongs—one related to sports, the other to autism. He has never had a romantic relationship and stated that he is not interested in pursuing one. He has a good relationship with his parents, whom he visits often. Howard likes to watch sports and regularly goes to sport events. He also likes to travel; he traveled in North America, Europe, and Asia, usually with his father. His other interests include photography and computers. He regularly does volunteer office work for a local autism organization.

Howard was diagnosed with Learning Disability in his early school years. Except for Grades 3 and 4, he attended regular classes, but had, as he put it “special help all the way through school.” According to the psychiatrist’s report, although “he has some learning problems his cognitive development was not delayed.” Howard was diagnosed with Atypical Pervasive Developmental Disorder (currently referred to as PDD-NOS) when he was 12 years old. Howard provided me with a one-page psychiatric report that contains his diagnosis, as well as a general description of his symptoms. The report also states that Howard was a patient for 16 years (at the time when the report was written, which was 7 years prior to the interview. However, the report does not say when or where Howard was diagnosed; from Howard’s spontaneous reference to a pediatrician with expertise in autism, it appears that he was diagnosed by that individual. According to the psychiatrist’s report, “his impairment in the development of reciprocal social interaction is not severe enough to make a diagnosis of Autistic Disorder.” Howard has been in psychotherapy for at least 17 years. He also takes antidepressants. He said that before he started to take medication, he was “hyper” and “I would go crazy. I would kick walls,” but he does not remember these incidents, and only knew about them from what others had told him.

Despite coming for the interviews right after work, Howard looked fresh and his movements and voice were full of energy. He never gave any indications of being tired. For most of the interview, he appeared very content and relaxed and had a smile on his face. He also often
chuckled and laughed at his own witty comments, making me laugh with him. He made good eye contact, as well as appropriate hand gestures. He spoke rather fast, occasionally omitting some sounds, making it at times difficult to understand what he said. He also had difficulties pronouncing some words, and, from time to time, I needed to ask him to repeat what he said or to ask for confirmation of what I had heard.

Howard’s voice and facial expressions, as well as his general demeanor changed noticeably with the topic of the interview. Thus, it was very obvious that Howard enjoyed talking about good aspects of his life, such as his job, his hobbies, and his accomplishments. He smiled and laughed, his face was glowing, voice crisp, and he answered immediately—sometimes starting even before I finished the question. His answers also contained appropriate amounts of detail. However, when the topic switched to negative experiences, everything changed: his facial expressions, the tone of his voice, and his answering style: he replied with either “I don’t know,” “I cannot remember,” or with a very general statement. In fact, he admitted that he “usually” does not talk about the “negative stuff,” and that he does not remember “bad” things. Because he earlier also said that he has a very good memory (and that that was his main strength), I confronted him with this contradiction, to which he replied, “I don’t like to remember bad things. Everybody knows that I wouldn’t talk about bad things [laughingly].” He then said that his memory for bad things is “terrible,” adding “[I] block them out of my brain [laughingly]. They get in, they leave. I don’t keep them in there [laughingly].” However, despite his attempts to dismiss the issue, his above-described change in both verbal and nonverbal behavior, together with one explicit refusal to elaborate on one of his general answers by adding, “But I don’t want to talk about it,” made me feel uncomfortable with asking him questions aiming to solicit negative life experiences, so that in the later parts of the interview, I withheld some of the usual probing questions.

Despite these qualifications, my main impression of Howard is that of a happy and jovial person who makes others feel good in his presence. He is obviously very proud of himself—his skills, his abilities, and his accomplishments.

Aside from the note from his psychiatrist, Howard also provided one published autobiographical essay, which, for the most part, contains the same information he provided in the interview.
9.1.2.7 Jimmy

Jimmy is a thirty-nine-year-old single man with a high school diploma and 20 years of work experience—mostly restaurant management—but currently unemployed. He lives with his mother in a city on the outskirts of a large metropolitan city. At the time of the interview, he was taking graphic design courses at a private college. Previously, he had gone to college three separate times, but never graduated. Although he did not have a romantic relationship at the time of the interview, Jimmy reported having had such relationships in the past, one of which involved living together with his girlfriend for couple of years. Jimmy reported having good relationships with his mother and with his younger sister and her family. He is particularly fond of his young niece. After his parents divorced when he was fourteen, he lost touch with his father. Jimmy always liked arts. When he was younger, he liked to draw, but about a year ago he discovered his talent for photography, which is now his main interest. His photography, which he posts on the Internet, ranges from landscapes, to family scenes, to abstract. Jimmy also loves nature, reading, and listening to music.

In school, Jimmy always went to regular classes. However, he “always” had social difficulties, which he referred to as “being afraid of people,” “social anxiety” and “insecurities.” During his schooling, he was never referred for an assessment, but he started seeking psychiatric help on his own when he finished high school. He was first diagnosed with Social Anxiety and Depression, but most recently—only a month before the interview—he was also diagnosed with Asperger’s Disorder. Jimmy was diagnosed by a psychiatrist who wrote a one-page note listing which DSM-IV criteria he met. Jimmy started using drugs and alcohol when he was 15 or 16 years old. Although he said that he does not take drugs any more, he admitted to still having problems with alcohol. (Jimmy was the only participant who spontaneously talked about drug and alcohol problems.) He is currently in Cognitive Behavioral Therapy as well as on antidepressants.

Jimmy was very enthusiastic about being interviewed, and hoped that it might help him understand himself better, as well as help others understand autism. During the interviews, he was very soft-spoken, and his voice often trailed off by the end of the sentence, sometimes becoming barely audible; however, at this point he would spontaneously raise it. When talking about relatively more emotional issues, his voice often trembled. His eye contact was good, and
he often smiled and chuckled. Jimmy’s language included a lot of jargon. His answers were usually fairly short so that I often needed to encourage him to tell me more. Jimmy had some difficulty with providing examples to support some of his general statements and would express his frustration with this. In general, Jimmy left an impression of a pleasant and caring person.

In addition to the interviews and his psychiatrist’s note, I also obtained some information about Jimmy from two websites for which he provided links, and on which he posts his photographs. My own thoughts about his photographs as well as other viewers’ comments confirm Jimmy’s claim about his artistic sensibility. Jimmy also provided some additional information about himself in three follow-up e-mails more than a year after the interviews, from which I learned that in the meantime he had completed the graphic design course but that his employment status and living arrangement had not changed. However, in one of these contacts Jimmy informed me that he was starting to get some recognition as a photographer:

My photography’s been getting some attention lately. I have pictures up in two local galleries - just sold one. I just won first place in an art show [. . .] and I was the guest speaker at the opening of a local art exhibition [. . .]. I was also featured in two local publications. You can read one here: [link].

9.2 Pierre’s Interview Report

9.2.1 Pierre’s Self-Portrait

In this section I present Pierre’s view of himself as a person. The section includes Pierre’s self-definition, his perception of his strengths and weaknesses, his view of his autism, and his self-evaluation. (Because this section contains many excerpts from the interview transcripts, reading transcript conventions provided in Appendix D first may be useful.)

**Self-definition.** After hesitating a bit (“I don’t know what to say, really”), Pierre described himself as follows: “I guess you can say I am intellectual.” Asked to elaborate, he said, “I read a lot, especially Wikipedia” and “I have a PhD.” He also said, “Well, I’m a bit of a dreamer.” He elaborated, “I sometimes think about ways I’d like the world to be better” and “I sometimes
dream about having a girlfriend.” His final self-characterization was, “You can say I am anti-social, maybe,” for which he provided the following explanation:

I don’t have a lot of friends and such. I stay home a lot. Lately I’ve been trying to change that, through Meetup organizations . . . through Internet organizations like Meetup—Meetup is a way of people to get together for social events. I am even an organizer of one—it’s [Oscars] Meetup.

**Strengths.** Pierre believes that his greatest strengths are imagination, logical thinking, and loyalty. He said he uses his imagination, or his “willingness to think outside the box” when he thinks about political reforms (for example, when he designed a “scheme for introducing a proportional representation scheme in the Canadian parliament”) and when he reads about history (when he tries to “imagine things in different ways”). Pierre said he uses his second greatest strength, logical thinking, primarily for solving oekaki puzzles. With regard to his loyalty, the trait he likes the most about himself, he said, “I like that I am loyal” because “I like when other people are loyal.” He supported this statement by telling me about his loyalty to political figures.

**Weaknesses.** When asked about his greatest weakness, he immediately said “I can be indecisive—that’s the main reason I haven’t found a job.” When asked what he likes least about himself, he also chose indecisiveness. Asked why, he replied, “If you don’t make decisions you are avoiding life.” Pierre identified his tendency to get discouraged easily as his second weakness. He believes that this tendency has much to do with the way he currently lives his life. When asked for an example, he said, “I asked a girl out once, but she wasn’t interested, and it will be a while before I ask a girl again.”

### 9.2.1.1 Being Autistic

About his autism Pierre said, “I don’t feel like my autism is a real disability.” To the contrary, he said, “I guess, in some ways, I like being different.” He explained his answer by saying that there

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13 It is important to note two uses of the ellipses in the transcripts: (a) to indicate that the speakers did not finish their thought (in which case the regular ellipses are used, like here) and (b) to indicate that part of the speech contained in the transcript has been omitted (in which case the ellipses are put in brackets, like any other inserted material).
are many good things about being autistic. For example, he believes that two of his most valued abilities (logical and analytical) are related to his autism. He also said because he is autistic, “I’m not a conformist. I’m willing to, you know, like in that Apple computer ad, “Think different”—which ought to be “think differently,” now that I think of it.” Perhaps he expressed the best his stance on autism in his concluding remark of the following exchange:

L: And what would life be like if you were not autistic?
P: I couldn’t imagine being different.
L: Okay. But what do you think, would it better or worse, or the same?
P: I imagine it would be more conventional, and to tell the truth, I don’t want to be conventional.

9.2.1.2 Self-Evaluation

Pierre said that his feelings about himself are “neutral” and rated them accordingly as 3 on a scale of 1 to 5. Although he likes many of his good features (e.g., being logical, loyal, and imaginative), there are things about himself he is not happy about: “The way I look at it, heroes in the world are the people who get the work done—I don’t get that much work done. If I had an important job, then, maybe, I’d admire myself more.” He also does not like that he “sometimes feel[s] emotionally cold” and that “some people find [him] remote.”

When asked about aspects of him that could never change, he said his “ideals.” He elaborated: “I’m a leftist, and I want to change the world in a way that promotes justice.” Ask about other aspects of self that could never change, he replied, “It is hard to say. I actually think about that a little.”

9.2.2 Pierre’s Current-Life

In this section I present Pierre’s descriptions of several aspects of his current life: employment and financial situation, social life, and leisure activities. The section concludes with Pierre’s evaluation of his psychosocial adaptation.
9.2.2.1 Employment and Financial Situation

Pierre is currently unemployed, and he said he “feel[s] ashamed” of it: “I’m ashamed that I still depend on my family.” Pierre was quite vague about his future career prospects. He said he is not interested in teaching (“I’ve had my fill of academia.”) but that writing and research are possibilities: “Maybe I could write. Or maybe, do research.” He said he would be particularly interested in translating from Chinese and Japanese into English (he can read both languages with a dictionary).

On a scale 1 to 5, Pierre rated his satisfaction with his current employment status as 2. If he had “a full-time job in the sort of work that I like,” Pierre would have had rated it 5 (and jobs he has in mind are “jobs that involve writing”). He also said, “money isn’t that important to me—if I found the work that I really liked, it wouldn’t matter that much to me how much it paid.”

Pierre’s main source of money is the allowance he gets from his parents. (From Pierre’s diaries, as well as from the conversation with Pierre’s parents, I also learned that Pierre is involved in selling over the Internet his and his family’s books that they no longer wish to keep.) Pierre said that his financial situation is “okay for what I need now since I live with my parents.” Pierre initially rated his current financial situation 4 on a scale of 1 to 5 but later changed it to 3. He said, “If I had a full-time job, I imagine that would raise [the rating] to 5.”

9.2.2.2 Day to Day Life and Interests

Asked about his day-to-day life, Pierre reported that he spends 2–3 hours on the Internet (including reading the Wikipedia), more than 1 hour watching DVDs (he sees 2–3 DVDs a week), 1 hour solving crossword or oekaki puzzles, 1 hour reading books, ½ hour reading comics, ½ hour reading newspapers, and 10 minutes writing a diary (which is a total of about 7 to 8 hours a day). Although Pierre admitted to having some small rituals regarding the Internet (always starting with the same comics web page), he does not think that he has (nor that he ever had) any serious rituals or obsessions. In the past, he said, his main ritual was TV, but he added that it is so for other people too. Pierre also admitted to sometimes talking “a lot” with his family.
“about things from the past” that made him angry but said that his family would only “on occasion” tell him that he talks too much about these issues. Pierre could not remember anybody telling him specifically that he talks too much about any particular topic (as is often the case with people diagnosed with Asperger syndrome).

9.2.2.3 Social life

Pierre’s social life revolves around his family—his parents and siblings. The most enjoyable part of his current social life is singing in an amateur choir and an amateur opera chorus and karaoke singing. Although he considers four people his friends, he does not spend a lot of time with them. Two of his oldest friends (who are a couple) he sees several times a year. They usually visit each other and chat, have a meal, and/or watch a movie. Occasionally, they also go out together and have a meal, go to the movies or to an event together. He sees another friend, who sings in the same choir, only after their weekly choir practice, when this person gives him a regular ride home. Pierre only occasionally meets with his last friend with whom he discusses politics. He occasionally also socializes with other choir and chorus members and with other people with whom he participates in community work.

Pierre talked the most about his latest attempt at socializing through Meetup groups (groups formed around mutual interests and facilitated by an online social networking portal). He said he discovered this form of socializing in the newspaper, and he liked how it worked. He is currently an active member of several such groups. “I’m getting a lot of acquaintances—no close friends so far,” he said. Although at these meetings Pierre “let the other people do the talking a lot of the time,” he enjoys attending them. Although Pierre never had a romantic relationship, he is not disinterested in it. He said, “I remember, I once . . . I actually tried to get into Internet dating, but I couldn’t really get past the stage of writing a profile about yourself.” When asked why, he explained, “Self-promotion isn’t one of my skills.”

Pierre also said that “sometimes [he] find[s] it hard to be casual” or to “loosen up” and make a small talk. When asked what he finds particularly difficult about small talk, he said: “I don’t
know what to say, like, when we came in and you asked me, ‘How are you?’ I always have trouble answering that question because, on one level, I don’t really know how I am.”

On a scale of 1 to 5, Pierre rated his social life as 3. He elaborated, “I guess I’m more active than I used to be, but I’m hoping for improvement.” Had he had a girlfriend, he would have rated it 5.

9.2.2.4 Adjustment to the World

Pierre feels well adjusted to the world around him; he rated his adjustment as 4 on a scale of 1 to 5. “I considered ways I might be better,” he explained. “Maybe—if I had a job and a girlfriend, it would be 5,” he added. He said that his family also considers him well adjusted and that he does not know anybody who would not agree. Pierre is also very satisfied with his current life, and he rated it 4 out of 5. Out of his daily activities, Pierre said he enjoys reading comics the most. He could not remember any chores he currently has on a daily basis.

9.2.3 Pierre’s Life Experiences

In this section, I present Pierre’s descriptions of his personal history. The section begins with Pierre’s experiences related to his realization of him being different than his peers, and of his experiences related to his diagnosis of Asperger syndrome. The section also includes accounts of Pierre’s most important life experiences as well as his most disappointing, unhappiest, and happiest experiences. It further contains his descriptions of the turning points in his life, the most important decisions he made, and the most important lessons he learned from his experiences. The section also contains information about how much and with whom he talks about his life experiences. The section concludes with information about people he considers to have had the most significant influence on his life.

9.2.3.1 Being Different
When I asked Pierre about the time when he realized that there was something different about him, he replied as follows:

Oh, it was pretty early. I guess, when I was nine, I skipped the grade in school, and I was in class with people who were a year older, and in terms of social maturity, I was less developed than usual for my age.

When asked to say more about it, he said, “It isn’t fun being the least mature kid in the class because . . . paradoxically, it means the more mature kids will be immature at your expense.”

Our subsequent exchange went as follows:

L: And how did you realize that you were not as mature as others?
P: That’s hard to say. Like, for a while I saw it in terms of the way the other people were the problem.
L: Can you say a little bit more about it?
P: Oh . . . [pause] I guess, and then lately there was . . . and then grownups tried to pressure me to try to get me to ignore the people who bothered me.

When asked to say more about this “bothering,” Pierre described the following incident:

I remember one time—it was in Grade 6—when one kid . . . he was working with papier mâché, and he said to me, “Would you like some porridge?” [imitating]—porridge being something that babies eat. And once he bothered me . . . but then, I think, this [Jennifer], this really nasty girl . . . I think she overheard it, and then she started saying, “I-love-porridge” [imitating in a sing-song voice], and then everyone was saying it, or a lot of the class was saying it, even people outside the class.

When asked how he felt at the time, Pierre said, “I didn’t like being reminded that I was the baby of the class, being the youngest, or one of the youngest.” He remembered that it particularly bothered him because “there was nothing I could do about it.” His parents and teachers told him to ignore his bullies, but he could not do it all the time: sometimes he got angry at himself, other times “I got angry with them [his classmates], except that grownups didn’t approve of me getting angry—they wanted me to ignore it.” Getting angry led to several things: “At first, I just said angry things, but I remember Grade 7, it got to the point that I started hitting people.” Pierre remembered one of these episodes which was, according to him, prompted by a decision of one of his teachers “who had it in for me” to assign him to do the group project with his bullies:
When I was twelve or so, I remember there was one incident, where [...] a science teacher, and it was a science experiment—normally we did these experiments in pairs, buddy system sort of, but this was a complicated experiment, where it was done by four people, instead of two, and she [science teacher] matched me with two people she knew I didn’t get along with. And as a result, I ended up hitting one of them, and she sent me to the principal’s office, and my parents were really angry about it, and they even took me out of school for a week—until they lost their nerve.

Pierre’s parents “lost their nerve” approximately two years later (when Pierre was fourteen), and they took Pierre out of school and enrolled him in correspondence courses. However, memories of these events seemed to be overwhelmingly painful for Pierre to talk about, so he chose not to—at least not at that moment. (He said, “There was another incident where . . . I don’t wanna talk about it so much.”) It is important to note, however, that Pierre does not think that he ever “bothered” other children first: “My general policy was that if people left me alone, I’d leave them alone.” When Pierre came back after a year of correspondence courses, bullying continued and lasted throughout high-school. “I think about it a lot, I admit,” he said. When asked why, he replied, “It happened to me at an important time in my life.” He added, “I still get angry. I guess, what really angers me today is that . . . I felt that . . . grownups who wanted me to ignore them were, kind of, blaming the victim.”

9.2.3.2 Getting Diagnosed With Asperger Syndrome

It was not until he was 39 that Pierre got diagnosed with autism. It happened after he got his PhD degree and started to feel unhappy with his life, particularly because he “hadn’t got a job,” or rather, he could not look for one because of his indecisiveness.

When he got diagnosed with Asperger syndrome, Pierre was skeptical about it, and he still is. He said, “I just couldn’t imagine myself as being that different.” For Pierre, it just “sounded too neat—having some big condition that explained everything.” However, he does believe that he “could have it,” although he is “not totally sure.” He said, “I just don’t think of myself as having some big condition.” Rather, he said, “I just think of myself as just being different.” He later added, “I see it’s just one part of me that may or may not explain a whole lot.”
Regarding his reaction to receiving the diagnosis, Pierre said that he “liked the idea of having a new category of people to be in.” He also said, “I liked having the chance to look at myself in a new way.” However, Pierre did not spend too much time trying to learn about autism. He said, “I wasn’t in a hurry to read about it.” He read a little bit about it on the Internet and “glanced through” some books, but did not read them “from cover to cover”—just “here and there.” (When reading the interview transcript, Pierre made the following addition: “Now that I think of it, I’ve read Mark Haddon’s novel *The Curious Incident of the Dog in the Night-Time.*”\(^{(14)}\) Asked about any influences of getting the diagnosis on his life, Pierre said that it allowed him access to an agency that specializes in providing job training to autistic individuals and that he got his first and only job through this agency.

9.2.3.3 The Most Significant Life Experiences

Pierre had a difficult time deciding which of his life experiences were the most significant for the kind of person he is now. He said, “I’m not sure really what’s important to me” and “There are couple of events—I’m not sure how important they are, but I think I should mention them anyway.” Subsequently, Pierre talked about a number of “important experiences” but found it difficult to evaluate their relative importance for his life and the kind of person he is now. He also changed his mind several times regarding the order of importance of experiences he talked about.

9.2.3.3.1 Skipping a Grade

Pierre started talking about his experiences associated with skipping a grade in the same manner in which he talked about other things, slowly and without emotions. However, he soon changed both the speed of his talk and the tone—he started to talk faster and louder, becoming visibly upset and angry:

\(^{(14)}\) This popular novel, whose main character has Asperger syndrome, was published in 2003, a year after Pierre got diagnosed.
After I skipped a grade, anyway, I was absent from school quite a bit—not because I was sick, just because I . . . I couldn’t take it. [...] Anyway, when I had been absent from school that day and I went out in public anywhere where other kids were, they’d make an issue of it later on that I hadn’t been in school, but I’d still gone out later that day and, like, the parents said that I shouldn’t care about this, but it did get to me. And, you know, there was one incident . . . it was near the end of the year when I missed one day, and . . . anyway, my brother and sister were at this sports day event that was down on the university campus—we lived in a university town—and my mother got the idea that I should bicycle down and see them there, and I didn’t want to do this because I didn’t want to go out in public on days when I wasn’t in school, and the last thing I wanted to be doing was to be seen riding my bike around, and when I told my mother I didn’t wanna go, she got angry. And, you know, sometimes parents see what they want to see. And anyway, the result of that was that I did bicycle down. The result of that was that a few days later in school, the teacher said to me, “Instead of riding your bike, you ought to come to school” [imitating], which meant that I had been seen. And for the rest of the year, several times, other kids would say to me, “Don’t cry [Pierrot] [diminutive form of his name], mommy will always let you ride your bike, instead of going to school” [imitating]. And I got angry about that because . . . well, it’s bad enough when you make your mistakes, it’s worse when people . . . when you do someone else’s mistake.

When I asked Pierre what he made out of that experience, he said, “That parents live in their own world and that sometimes the only thing you can do is fight them and be unreasonable.”

However, when asked whether he did that after these events occurred, he replied, “Well, not immediately” and started to describe another incident of similar nature which ended with him yelling:

And, anyway, just the next year there was this other incident, [pause] like, I missed a lot of school in my next year—I was Grade 6. And the teacher . . . he gave me some trouble about it—he spoke to me about it, and the only thing I did was, I stared blankly and just said nothing because there was nothing I could say that would do any good. And he actually got my hearing tested—it turned out I had perfect hearing. Anyway . . . but it did get to me, and so at the end of the year I decided that for the last month of school I’d avoid missing any school at all—that was my idea. I even went to the sports day, even though I knew I was going to hate it and I did, but I tried to . . . but in the end, I couldn’t, and it got that I just had to be absent one day—not because I was sick but just because it got to me, like, just being there was hard work. And what happened . . . that night there was . . . I was in the church’s junior choir, and there was a rehearsal that night—it was the last rehearsal before the-end-of-the-year concert. I remember, [Jane], my sister, like, she was kind of a micro manager, like, she always knew what was best for me—better than I did—or at least she thought she did. I remember [Jane] saying, “I think [Pierrot] should go to choir practice anyway,” [imitating] and then my parents gave me trouble about that. And even then, I still would’ve resisted, but then my other sister [Mary] . . . she tipped the balance in getting me to go there and I . . . I remember when I was there at choir practice . . . I remember this girl [Jennifer] [a classmate mentioned in the first
interview as a “really nasty girl”), she said to me, “Why weren’t you in school [Pierrot]?” 
[imitating] It wouldn’t have been so important except that she *blabbed it around* that I’d been to choir practice when I hadn’t been to school that day. The next day at recess, I had to do this . . . the kids gave me trouble about, and I just . . . I just couldn’t deal with it [emotionally]. I let [Mary] convince me that it was something I could deal with, but I just couldn’t—it just got to me. I remember, I pleaded with them. I said, [starts speaking faster] “LOOK, I JUST COULDN’T MISS IT,” like that was going to do any good—they were determined to have their pound of flesh [fast speaking ends]. [exhales through his nose loudly; looks upset and angry]

**When I asked Pierre how he was feeling now while talking about these events, he said, “I’m still angry” and explained why:**

Like, it wouldn’t have mattered so much if they’d pressured me into doing it because it was in their interest, like, that’s the way of the world . . . what bothered me is that they’d decided that this was in MY INTEREST.

He said that he also “felt pretty angry about it” back then, but when he told his mother what had happened, her reaction was not in any way helpful to him. To the contrary:

I remember she said, like, “Next week it’ll be [speaking very fast] the last . . . the end of Grade 6, and then you won’t have any more recess when you have to deal with that.” For me, that was a scant consolation—I had to go through this one more time [emotionally] because my family decided this was best for me. Like, they felt I was too sensitive, and I suppose I was. But the thing is that this way of dealing with it, like . . . it didn’t solve the problem—it just . . . it undermined my trust, really.

Yet, when I asked Pierre to think back about this event and tell me what kind of resolution he would find helpful, he said he did not know and continued to tell me about why it bothered him so much:

I don’t know. Like, it doesn’t bother me all the time, like . . . it bothers me on occasion when I’m in a bad mood—when I’m kind of depressed anyway. I guess the thing is, at the time I felt *really* stupid, like, I *knew* what the consequences would be if I did what they wanted, and I knew I couldn’t deal with it, but I just . . . but in the end, I let them wear me down—I took the path of least resistance—and I paid the consequences.

Similarly, when asked about the time when he started doing things his way, he replied, “Well, there were other times when I didn’t let them make me do things, but I remember the times when I did do it their way and regretted it.”
When I asked Pierre how he thinks his life would have been different had these events never happened, he first replied with, “I don’t know” but then said, “I guess, maybe I’d be more trusting of people—I’m not sure.”

9.2.3.3.2 Moving and Starting the PhD Course

Pierre chose moving to the city where he now lives and starting the PhD program, when he was 28, as the second most important experience of his life. He said this experience was important “because that was the time I started having some more independence. Before that, I’d been living with my parents almost all the time.” Because Pierre was living with his sister at that time, he was not “completely independent” but was more so than before. However, when I asked him how his life would have been different had he not moved, he replied, “I don’t know.” To my invitation to try to imagine one possible way it could have been different, Pierre replied, “It’s hard.” When asked about his feelings about himself at that time, he said, “Well, it was a time of flux, as they say—it was a time of new experiences.” He said he started to have some new interests then, such as “reading a lot,” especially reading books from the university library. When asked about the learning value of this experience, Pierre replied, “I can’t think of it just at the moment.”

9.2.3.3.3 Going Online

At our last meeting, when we were reviewing what he told me up to that point about his important life experiences, Pierre said, “And I suppose, I should mention 1996—I started going online and having connected to the Internet.” Because Pierre had already told me about three “most important life experience,” I asked him whether this would be more important than the experiences he already told me about (the year he took correspondence courses, which I will describe next). He replied, “Actually, it’s hard to say . . . well, it’s my most important recent experience, I guess.” In the end, he decided that it was more important because it was more recent and because “it made a big change in my life. I spend a lot of time on the Internet.” He also said that it was important because, “I started expressing myself more” through participation
in web forums where “I met an interesting community” and where “I got to talk about different things.” Pierre visits these forums daily and he often posts comments, usually about film and politics. He also said that the Internet allowed him to use a social networking venue Meetup to meet people in person, not just virtually (as previously described). Pierre said that the Internet also allows him to find “a lot of information” that interests him such as poems, biographies of poets, and information about actors.

When asked how his life would have been different without the Internet, he said, “It’s hard to imagine. I would probably be bored.” Asked whether he was bored before the Internet, he replied, “Not really,” and corrected his previous answer, “I would be probably watching more TV.” When asked how the Internet changed him as a person, he said, “It’s hard to say.” (Importantly, Pierre gave the same answer to my question about the importance of experiences related to the year of the correspondence courses.)

9.2.3.4 Most Disappointing Experience

Pierre was 14 years old when his parents took him out of school (because he was becoming aggressive toward his classmates who bullied him) and enrolled him in correspondence courses. This was a truly unhappy experience for Pierre, and memories about it still elicit very intense emotions. Talking about it made Pierre upset:

What happened was . . . when I was fourteen and a half my parents took me out of school and had me take school courses by correspondence, and it was a very bad experience for me because the markers I was dealing with were tactless and . . . [pause] I remember when I took my first lesson in math . . . I remember this problem involving a Venn diagram [. . .] the answer was nine for this, so I wrote nine people. The problem was there was a mark next to it, so the mark made it look like 91 people. Now, he could’ve figured out that I meant 9, if he just looked at the diagram I wrote [speaking fast and looking upset], but he wrote in the diagram, “too small and messy.” And then he said I had the wrong answer, and he said, “Do over properly”—exclamation mark. And when I got it back, I cried at first, then I got angry that he hadn’t even looked at my work. And when I told my parents about it, I wanted them to complain to the people in charge, and they said, “We aren’t going to have anything to do with him because he is unreasonable.” Well, like, they were rewarding him for being unreasonable. They were cowards, I felt.

Pierre also remembered a similar incident that happened to him later in a regular school class:
What happened was, like, we were supposed to write down our name and address neatly. Anyway, I heard the teacher’s voice behind saying, “Oh that lettering, oh that numbering” [imitating], pointing out that I . . . he was dressing me down in order to impress the others. And I wanted my parents to complain about him, but they said, “We aren’t going to have anything to do with him because he is unreasonable” [imitating].

Pierre said he wanted to talk about these events because they still make him angry. He also said that those were the times when he was disappointed with his parents because “they made the decision to move me in these correspondence courses without really consulting me [. . .] they simply made the decision for me.” He explained how these events are related in his mind:

The important thing, I guess, is that I felt that I was being left on my own to deal with my problem [long pause] which wouldn’t have been so bad except that . . . I guess, the case with the correspondence courses . . . like, I ended up being rude with them—with some markers—because I was so angry . . . and my parents got judgmental—they disapproved of me. They tried to make me apologize to them. [. . .] I felt that they were . . . they had a double standard there—that the feelings of these markers were more important than my feelings—because I was just a kid.

When asked how these two events influenced his life, Pierre said, “I guess, that’s hard to say, I guess. I have a long memory. A long harsh memory. That is, you could say I hold grudges.”

When asked whether he learned something from this experience, Pierre said, “I learned that my parents were unreliable at key moments.”

When I first asked Pierre to choose his three most important life experiences, he talked about the year of the correspondence courses first. As mentioned above, he later changed his mind about its importance. Similarly, when I asked Pierre about his most disappointing experience, he again first said “the year of the correspondence courses,” but later he was not sure about that and mentioned other disappointing experiences asserting that disappointments could not be measured:

P: I suppose there are some other periods, like, there is a period, like, just before—the year or two before—I moved to [Montréal], I felt kind of disappointed because I wanted to become independent and get on my own, but I was still living with my parents then.

L: Uh-huh. Okay. So would that be the second time when you were the most disappointed?
P: [long pause] That’s hard to say. I guess, another time I was disappointed within the last years of my PhD when I ended up writing ten drafts of it. I was stuck with a supervisor I couldn’t work with, and I couldn’t replace him because there was nobody else.

L: Okay. I would just be interested to talk a little bit more about whatever feels to you most disappointing in your life, so if we can just go back a little bit to that event.

P: And I guess I should also mention I’ve also been feeling disappointed in the last few years after I finished my PhD since I am still unemployed.

L: I see. So there have been a lot of times in your life, when you were disappointed. [P: Uh-huh.] Okay, so would you be able now to choose one of these events as one that feels to you as the worst one, or when you were the most disappointed?

P: [long pause; inhales and exhales loudly] I just don’t know. To me, disappointed isn’t something you can, like, measure.

When I then asked Pierre whether the year of correspondence courses is one of his most disappointing experiences, he said yes, and we left it at that.

9.2.3.5 Unhappiest Experience

The year of correspondence courses was also the time when Pierre felt most unhappy. Pierre started talking about it in his usual emotionless tone, but as he talked and as more and more unhappy memories came back, so did accompanying negative emotions:

P: I remember what happened . . . one thing that angered me was that it went on so long, like, first . . . like, we first applied in October and it was two months before I got my first lesson. Then, like, it was a series of 20 lessons—except in English, it was 25. I had this idea that I wanted to finish in June, like, the time when regular schools finished, but it took a long time, like, it wasn’t until the end of June that I finished the main lessons, and then there were still more corrections to do, so I finally got my final report card three days before I started school the next year.

L: Uh-huh. And how would you sum it up—why were you the most unhappy that year?

P: I guess there was . . . a lot of things made me angry, like, the history marker was always telling me to do stuff over because it was too brief. What angered me was that they hadn’t told me how long it was supposed to be in the first place. They were disorganized. [. . .]

L: I see. So you didn’t get what you expected—it wasn’t the way you expected, and all that. Okay. Is there anything else you want to share about that experience?

P: And I remember, like, one lesson I sent in was pretty messy—the thing is that I didn’t have time to do it over more neatly because I had five other courses to think about, and I remember my . . . [takes a deep and loud breath and grunts] my
history marker, I remember he . . . he . . . he . . . pointed to one messy exercise and he said, “You can do much neater than that, Pierre,” and he underlined “that” [starting to yell]—THAT IS DELIBERATE HUMILIATION, AND THERE IS NO EXCUSE FOR DOING THINGS THAT WAY [said faster with a change in facial expressions and color]. [grunts]

L: I see. It still makes you angry.
P: YES, VERY ANGRY. [yelling with changed facial expressions] [L: I see.] And what made me especially angry was that my parents wouldn’t DO anything about it—they were afraid of him. There was no excuse for people doing things that way.

L: Uh-huh. And if you are feeling about this like you are now, how did it make you feel then?
P: Oh I . . . well, I ended up having an ulcer.
L: Uh-huh. So it affected your health?
P: Uh-huh. I was in the hospital later that year.
L: Uh-huh. For how long were you in hospital?
P: A week or so.
L: I see. Okay. And when you think about it now, what kind of importance does it have for your life? [pause] One of the things I see, it still makes you angry, right? [P: Uh-huh.] At that time it made you also physically ill [P: Yes.] because you went to hospital . . .
P: I guess it angered me that my parents were so passive about it. [exhales through his nose noisily]
L: Uh-huh. But in general, how would you evaluate its importance for your life—for the kind of person you are now? Did it influence you becoming a certain kind of person?
P: Oh I . . . I suppose—maybe it did.
L: Uh-huh. Could you elaborate?
P: I just don’t know.
L: Okay. So what would be the lesson that you learned from this, if anything?
P: [exhales loudly] I don’t know. [exhales loudly]

At this point I felt that Pierre was still very upset by the memories he just told me that he needed some time to recover, and after I asked him whether he would like to have a break or stop for a day, and he chose to stop, we ended our session. (On our way out from the interview room we talked about other issues—singing, reading, and a trip he was planning, and Pierre seemed okay; that is, he did not seem upset by the emotional memories any more.)

9.2.3.6 The Happiest Experience

The year Pierre spent abroad researching for his PhD thesis when he was 33 was his happiest experience:
Because I enjoyed doing the research, but I was also staying at a [Trinity] College—the residence for doctoral students. And I was in a lot of activities there—I was in the video club, I was also in the choir. And it was the time when I was away from home, and I enjoyed it.

This was the first time Pierre was away from his family. Although he spent 3 years previously living away from his parents but still living with his sister “this time I was away from my whole family.” Pierre said he particularly enjoyed this time because it allowed him to make his own decisions:

I liked making my own decisions, like . . . something I particularly recall . . . I enjoyed shopping at the Safeway supermarket there. I just enjoyed it because it meant making my own decisions about what food to buy and such.

Pierre said that during this time “I learned that I can be independent.” He also talked about a mistake he made with regard to where and when to go shopping, concluding: “To tell the truth, I was kind of happy that it was my mistake, not something I’ve been pressured into doing.” Although he did not spontaneously mention any friendships he made while living abroad, when I asked him about it, he recalled one friend who had similar interests—in film and opera—and with whom he spent a lot of time. However, they “fell out of touch” after he returned home.

9.2.3.7 Turning Points

Looking over his life, Pierre recognized several events as turning points. The first of these events was the time when he skipped the grade in school. Asked to say how his life looked like before he skipped the grade, he said, “My life seemed simpler,” while after, “I felt I was in a difficult situation—one that I couldn’t handle so well.” Starting university was a second turning point in Pierre’s life. At university, “I was less troubled—I didn’t have to be in the presence of people who enjoy making my life difficult,” said Pierre. The third turning point was when Pierre switched his studies from mathematics to history. Although he initially said that this had an impact on his independence, he later realized that his life “wasn’t that different actually” after he changed the course of his study. Another turning point was “when I moved to [Montréal] and started my PhD, and my parents were still living in Alberta then.” The significance of this
change for Pierre was that he felt more independent after he moved and because “there were a lot of new experiences—living in the city.”

9.2.3.8 Most Important Decisions

In his mid 20s, Pierre made his first important decision—to switch from studying mathematics (where he got his BA) to studying history (where he got his Masters and PhD). When I asked Pierre about the influences of this decision on his life, he said, “I guess, history interests me. I guess, I’ve learned a lot of stuff.” Asked whether he thinks his life would have been much different if he did his PhD in math as opposed to history, he replied, “I suppose it might have been.” When I asked in which way, Pierre replied, “I’m not the type who imagines the road not taken” and asked me if I have heard of Robert Frost’s poem *The Road Not Taken*. He then recited:

Two roads diverged in a yellow wood / And sorry I could not travel both / And be one traveler, long I stood / And looked down one as far as I could / To where it bent in the undergrowth.
   I shall be telling this with a sigh / Somewhere ages and ages hence.

Pierre also recited another Frost poem:

The way a crow / Shook down on me / The dust of snow / From a hemlock tree / Has given me [*sic*; “my heart”] / A change of mood / And saved some part / Of a day I had rued.

When I asked Pierre what the poem mean to him, he replied, “the point is about how we end up thinking about how things we might have done differently . . . and what would’ve happened, and the things is, I don’t think that much about that—I worry about the roads taken.” When I asked how he does that, he said, “I guess . . . trying to figure out what to do next.” Asked for an example, Pierre was not able to remember any particular experience. With regard to the impact of his decision to switch to history, he said that he “enjoyed studying history” and that he never regretted making that decision—if he had the chance to make a decision about his PhD again, he would make the same decision.
The second important life decision Pierre made was the choice of the university where he would obtain a PhD degree. Contrary to the first decision, he said he regretted his decision of university. He did not get along very well with his supervisor whom he could not change because there was nobody else on the faculty with expertise in his area of study. When I asked Pierre how his life would have been different had he chosen another university, he said, “Then I could’ve done something about my situation—I felt kind of helpless at the time.”

Pierre also said, “Another thing I’d do differently is I would’ve developed my singing talent more when I was young. [...] I might even have developed my acting talent.” (Although Pierre has been taking several acting and singing courses and lessons, he is fully aware that he does not have much of a chance of finding a job in any of these areas.)

9.2.3.9 Learning from Experience

After saying that he cannot “single out particular experiences” from which he learned important life lessons, Pierre accepted to talk about lessons he learned from his own experience:

It’s important to try to make your own decisions—to not let other people make decisions for you. I feel, like, if I insist in making my own decision, and it turns out to be a mistake, at least it was my mistake. The worst thing is when you let someone make a decision for you and it turns out to be a mistake, then you feel bad about it.

However, when I asked Pierre about experiences from which he learned this lesson, he made a pause and replied, “I don’t want to talk about it, can we talk about it later?” When we revisited this question again in our last interview session, Pierre said, “That’s hard to say,” and added, “I feel like I’m always learning things—it’s hard to single things out.” Pierre’s answer to a subsequent probing question was, “I can’t think of anything at the moment.”

9.2.3.10 Talking about Life Experiences with Other People

When I asked Pierre whether he talked with other people about events from his life that he told me about, he said that he talked with his family about the unpleasant events that still make him
angry, but not until he was in his late 20s, and that he also talked about the same events with some university counselors and with his psychiatrist. When asked whether he found that talking helped him, he replied, “I suppose it did.” He said, “I guess it was helpful just that I’d said where I stood—that gave me some satisfaction.” Although he also said that “these things are so complicated—they are hard to resolve” by talking, he admitted that “maybe [he] made some progress” after he talked to his parents. When I asked Pierre whether he talked to other people about his happy experiences, he answered, “Occasionally.” Asked with whom, he said, “It’s hard to think of at the moment.”

9.2.3.11 Significant Influences

Pierre believes that his family members had most important influence on his life because he “had the most contact with” them. He said, “I always felt I was learning from them” emphasizing the fact that he is the youngest in the family. When I invited Pierre to think about his life if he had different parents, he replied, “I can’t really imagine having a different life. You know the story how every kid has this fantasy that he’s adopted and that his real parents were someone different—well, no, I never had that fantasy.” When I asked Pierre how he sees influence of his siblings on him becoming a person he is now, after a long pause, he said, “Well, that’s kind of hard to say.” (He then quickly added, “I know this must be frustrating—not being able to be more specific.”) Although Pierre said that “maybe the teachers and people I met in school” could also have been important, he could not think of any particular teacher or any other person that was particularly important in his life.

9.2.4 Pierre’s Future Orientation

9.2.4.1 Endings of the Book about Pierre

When asked about his future, Pierre said that he “sometimes” thinks about it and that he talks “a little” with his parents about it. “When I was in that job training program, TFC, I talked about it with them too,” he added. When he talks with his parents about future, he talks about “what sort of job I’d like to get.”
When I asked Pierre about the future he would like to have, he replied, “I don’t really know” but later said, “I’d like to get a job.” He said he would like if he got a job while he is still in his 40’s, and if job “really uses my talents, something like . . . I think I might be good at translating.” With regard to the area in which he would like to translate, Pierre said, “Anything that interests me.” Pierre would also like if he could get a girlfriend, in the same timeframe, but he was unable to be any more specifics. He would also like if he “gained political influence and made the world a better place.” This, he would like if it would happen when he is in his 50s and 60s. Finally, he would also like to have “a home of his own [. . .] maybe in Vancouver or New York City.” (Pierre used a third-person pronoun in response to a request to talk about his future as if he were talking about somebody else; that is, as if he were reading the ending of a book about him.)

Pierre would also consider it a good future if he “became a writer and started writing good books.” When asked what kind of books, he said, “That’s another good question.” Asked whether he would like to have a wife or a family one day, he replied, “Oh, I . . . I like the idea of having a wife someday. Not so sure about family.” When asked whether he would like to get some new friends or to spend more time with friends he already has, he replied, “I think I’d like to get new friends” with whom he could, for example, sing and go for walks.

When asked about the ending for the book about him that he wouldn’t like, Pierre said, “The ending like this: “Nothing much else happened to him,” and then added, “and he continued to live with his parents.”

Asked how confident he was that his life will continue in one of the ways that he would like, Pierre replied, “I’m basically optimistic” and estimated his confidence at 60%. His confidence that he will avoid the worst possible life that he described was 70%. Pierre believed that his future depends 80% on him and 20% on unpredictable things in life including influences of other people.

9.2.4.2 Goals and Wishes
Pierre’s most important goal over the next 5 years was to get a job. In order to achieve it Pierre said he needed to “find a new job training organization. In fact, Father’s found one. He thinks it has possibilities. The first thing, I’m going to do is update my CV.” He said he planned to update his CV “this week sometime.” He also acknowledged that his indecision could be a potential obstacle to achieving this goal. He said it may prevent him from knowing “in which direction not to work toward.” When asked how he could deal with this obstacle, he said, “I guess, I can try to be decisive.” He also said he tried that “sometimes” before. When I asked him to elaborate on that, he compared himself with a soldier in a boot camp from a documentary he had seen. Despite trying hard, this soldier could not see what looked like a simple and obvious solution. He ended the story relating it to how he felt:

It was like he [the soldier] had done nothing, and the line behind him of other soldiers got held up, and all he could do was drop off into the mud below. My point is, that’s how I feel sometimes. I worry that when I try to do something it won’t do any good—and I might as well not have done it.

When asked about the next step toward achieving his goal or a backup plan, Pierre said he did not have any.

Pierre’s second goal was to get a girlfriend. He said it was a “pretty important” goal. However, he said he did not have much luck so far and that in order to achieve this goal he had to overcome “a certain measure of shyness.” He also said that the dancing lessons he took for over a year 5 years ago (he also mentioned how much it cost him), made him “somewhat less shy.” He also found singing in the choir and the opera chorus helpful in this regard. At the time of the interview, Pierre was not doing anything specifically related toward achieving this goal, and he agreed with my proposition that this “goal” was more of a wish than a goal.

Pierre’s third goal was “getting a new home.” He said, “I’m ashamed, kind of, that I still live with my parents.” He acknowledged that the main obstacle to achieving this goal was not having a job and that in order to achieve it he would first need to get one.

Not surprisingly, Pierre’s two main wishes were the same as his main goals: getting a job and a girlfriend. He wished to get a “good job” that he “really enjoyed.” He said, “How good the pay
was, wouldn’t be that important if I enjoyed the work enough.” Pierre also said, “I’d enjoy working in the library—just being around the books all the time.” For his last wish Pierre chose, jokingly, to “be the king of the world, so I could ration gasoline and stop global warming, and things like that.” He then added laughingly, “Come to think of it, being a king of the world would be job in itself.”

When asked what kind of person he would want to be if he could choose to be any kind of person, Pierre offered a description of one episode from a *Harry Potter* book before relating it to his answer:

I’d probably be a Casanova type, something like that [chuckling]. A ladies man, that sort of thing. But . . . funny, it would be enough to have one lady—if I could just be like that with one, that would be enough.

When asked whether he believed he could really become like that (with one girl), he replied maybe, but that it would also depend on the other person. When asked what would depend on him he said, “That’s hard to say since I have so little experience in that.”

9.2.4.3 Living in Another World

Although when Pierre was young he felt that he was living in a different world than people around him, he does not have the same feeling “so much lately.” He also said that he never imagined another world in which he would prefer to live. However, he would like if the world in which he does live could be a “better place for everyone”—and he had many ideas about that—but he “wouldn’t know how to make it better for people with Aspergers.” Asked how it could be better for him, after a long pause, he replied,

I guess, maybe if I knew what people like me were needed for. . . . That is, what sort of skills of mine are in real need that I should be offering—to put them to use for. [. . .] Like, I know I have some skills, I’m just not sure about what use the world would put them to.

9.2.4.4 Better Life
If Pierre could choose to live another life, he said he would probably choose to be an artist, such as a song writer or an opera composer. However, he did not believe that he had potential for that, “Well, I think if I had that potential, I’d know it by now.” Initially, Pierre found it “hard to say” what could never change about his life. However, he then acknowledged, “I couldn’t imagine living in the American Sun Belt [. . .] places like Florida and Texas [. . .] because they have such different values from me as a Canadian.” When in a follow-up interview I asked him what he meant by this, he explained:

I’m a socialist. I believe that government should be used to make things better for everyone and that government shouldn’t be afraid of taking on a big business. And also I am not anti war, but I am anti pro-war—I don’t like the way . . . like some people, like, they say, “When in doubt drop a thousand bombs on it.”

9.3 Interpretive Summary

9.3.1 On Pierre as a Person

9.3.1.1 On Pierre’s Self-Definitions

9.3.1.1.1 On Pierre as Intellectual

Pierre described himself as an intellectual, and not only did he offer valid explanations for this self-characterization, but, by using his knowledge of literature, film, and politics to illustrate his points throughout the interview, he also demonstrated its appropriateness. Pierre’s diary also corroborates its validity: it contains almost daily entries about books he read (both fiction and non-fiction), films he saw (both documentaries and feature), things he learned on the Internet (on a variety of topics, from velomobiles to Meiji-era Japan and Peloponnesian wars), public lectures and discussions he attended (e.g., on eco-friendly buildings), and/or puzzles or math problems he solved or was working on.

Pierre’s self-description as an intellectual person is also consistent with literature on autism: intellectualism of individuals diagnosed with Asperger syndrome is often described in both clinical (e.g., Asperger, 1944/1991; Attwood, 1998, 2006; Bosch, 1962/1970; Gillberg, 2002; Kanner et al., 1972; Tantam, 1991) and autobiographical accounts of high-functioning autistic individuals (e.g., Grandin, 1995c; Jansen, 2005; Schneider, 1999). As children, they are often
called “little professors” because of their advanced knowledge base in particular areas (Attwood, 2003; Baron-Cohen, 2000a; Baron-Cohen & Wheelwright, 1999; Gillberg, 2002; Tantam, 1991), which inspired the popular press to re-label Asperger syndrome as “the little professor syndrome” (Osborne, 2000). In their adult lives autistic individuals continue to pursue their intellectual interests in a way usually described in psychiatric literature as “amassing” facts (e.g., Volkmar & Klin, 2000, p. 37; Wing, 1981) or as “building up collections of knowledge” in psychological literature (Baron-Cohen, 2003, p. 144) or becoming “walking encyclopedia[s]” in autobiographical accounts (Schneider, 1999, p. 58).

However, many autistic individuals go beyond being “little professors” to become real professors; they include, among those who published their autobiographies: Temple Grandin (Animal Science, 1995c), Douglas O’Neal (Astronomy and Astrophysics, Prince-Hughes, 2002), Dawn Prince-Hughes (Anthropology, 2004), and Stephen Shore (Special Education, 2001); and among those whose biographies have been published: Richard Borcherds (Mathematics, Baron-Cohen, 2003). Like Pierre, many more of them obtained doctoral degrees (e.g., Liane Holliday Willey [1999], in Education; Therese Jolliffe [Jolliffe et al., 1992] and Wendy Lawson [2000] in Psychology; Kamran Nazeer [2006], in Philosophy; Barney Vincelette [2000], in Physics), double masters (e.g., Jean-Paul Bovee [2000], in Medieval and Roman History and Library and Information Science) and Penelope McMullen [2000], in Mathematics and High-Functioning Autism; and masters (David Andrews, 2006, in Special Education; Anne Carpenter, 1992, in Science in Librarianship; Marc Fleisher [2003], in Mathematics; Alison Hale [2005], in Physics; Bruce Van MacDonald [2003], in Physics; Chris Mitchell [2005], in Library and Information Management; Jessica Peers [2003], in English Literature; Jeanette Purkis [2005], in Art; and Jim Sinclair [1992], in Special Education). Many more obtained double bachelor and bachelor degrees (e.g., Sean Barron [Barron & Barron, 1992], in Journalism; Kathy Lissner [1992], in Political Science; Newport [2001] in Mathematics; Donna Williams [1992] in Sociology).

Yet, contrary to most autistic individuals whose interests are limited to a small number of more or less narrow areas, Pierre’s interests span a number of wide areas (several art branches, history, mathematics, politics, comics, and puzzles) that do not easily fit into a usual characterization of autistic interests. Therefore, autistic individuals’ referral to “love of learning” would be more accurate description of Pierre’s interests. As Edgar Schneider (1999) put it, “I have a love of
learning. I could even call it a voracious appetite” (p. 58). Similarly, Peter Jansen (2005) wrote, “I like to read and write and think; those are the things I do best” (p. 315), and Liane Holliday Willey (1999), describing her college experiences, wrote, “I loved academics and knowledge and scholarship and research and writing papers” (p. 57). From this perspective, it seems fairer to describe Pierre’s intellectualism by referring to his high need for cognition—a tendency to engage in and enjoy intellectual endeavors (Cacioppo & Petty, 1982)—rather than referring to a need for collecting facts.

Autistic individuals have also suggested that the need for learning could be a surviving strategy. According to Dawn Prince-Hughes (2002), “learning is keeping [autistic individuals] alive” (p. 122). Similarly, Temple Grandin (1995b) observed that high-functioning autistic individuals thrive particularly well in educational settings and that they sometimes become life-long students: “Some [autistic individuals] have become perpetual students because they thrive on the intellectual stimulation of college” (p. 46). Although Grandin was talking about perpetual college students, her characterization applies equally well to Pierre because he has not stopped learning even after he completed his PhD studies and continues to acquire further knowledge through self-chosen reading and a variety of continuing education courses.

9.3.1.1.1.1 Other Participants

Like Pierre, Jimmy also defined himself through reference to his intellect. He considered himself “relatively intelligent” because, “I’ve always felt I was a little bit smarter than average, like, I just, sort of, . . . I don’t know, I understand things—*certain* things—fairly easily. I like to think. I like to learn.” And, to provide some evidence for his claim, he said, “In my course that I’m taking now, my lowest mark is 98 percent.” (In a follow-up email, Jimmy noted that he completed his course with a 94% average.)

Although other participants did not define themselves in terms of their intellect, two of them—Geoff and Mike—made both explicit and implicit references to it during the interviews. For example, comparing himself to his ex-wife, Geoff referred to himself as “a bit scholarly” and also made many references to his scholarly knowledge. Similarly, Mike, who considered his
research skills his main strength said, “I do a lot of research—personal research, a lot of things.” One of these things is in-depth research (of literature) on autism, which he undertook in order to understand himself better; the other is his hobby, paranormal phenomena. Indeed, his remark about his ability to “find out information of facts and put together things of a research study” (about paranormal phenomena, which he posts on the Internet) could also be taken as an explicit reference to his intellect. Moreover, once he retires, Mike plans to “go to school” again.

Likewise, although Orville did not explicitly refer to himself as an intellectual, his account as a whole is a testament to his love of knowledge and learning. For example, he went back to college at age 47 and complained about the lack of opportunity to engage in philosophical discussions in the small town where he lives. He said that people there are not “interested in deeper, ethereal areas discussions dealing with science, philosophy, and other aspects of life.” As already mentioned, in his answers—many of which resembled theoretical discussions—he also made several references to philosophers and psychologists (e.g., Bertrand Russell, Erich Fromm) as well as to books and documentaries about the topics related to the issues he discussed. Here is an excerpt from one of his replies:

I believe that a lot of these things in us are ready. As Erich Fromm said in one of [his] books, the root of the word education in Latin doesn’t mean to put in, it means to bring out. That is, [. . .] education shouldn’t be to try and put something into a child, “Here’s your multiplication tables, learn it,” but to bring out. And I feel it’s the same with things like influence and that, that it’s already there, but it’s just a matter of somehow letting it come out.

Indeed, based on participants’ conversational styles and the conversation content, both during and outside the interviews, in addition to Pierre, at least 4 other participants in this study—Orville, Geoff, Mike, and Jimmy—could, from the third-person perspective, be described as intellectuals.15 For example, during the interviews, it was very obvious that these individuals liked to think, talk, read, and write about things that interest them—even do research. Likewise, after the interviews, they initiated small discussions about issues related to arts, science, and ecology, leaving me with the impression of having talked to very thoughtful and/or knowledgeable individuals.

15 In this section, I use intellectual in a broader sense, meaning “relating to the intellect” (ODE, 2005).
9.3.1.1.2 On Pierre as an Idealist and a Dreamer

Pierre said that he is an idealist and a dreamer and that he is imaginative. During the interview he provided several examples that he is as such—at least in the realm of politics. (His lack of interest and knowledge about the world of work could also be taken to mean that Pierre is certainly not a realist.) However, although Pierre said that he “sometimes dream[s] about having a girlfriend,” the lack of detail with regard to his own future puts a limit on his description of himself as a dreamer in the personal sphere. His diary corroborates this interpretation as it contains only several entries about his daydreams, all of which are rather general as the following example shows:

In the evening I went to a party at [Paul’s] house for MMP volunteers. I ended up playing the piano a bit. His cat [Maurice] sat in my lap and made me wish I had a girlfriend (one whose claws don’t need trimming). (September 29, 2007)16

Literature regarding imagination in autism is rather controversial. According to one influential and still widely used definition, autism is a disorder characterized by a “triad of impairments” which include social interaction, communication, and imagination (Wing & Gould, 1979). Moreover, impairment in imagination (i.e., “imaginative play”) is part of the diagnostic criteria for autism (APA, 1994, 2000). Finally, J. Craig and Baron-Cohen (1999) provided some experimental evidence for an “imagination deficit hypothesis of autism.” They claimed that autistic children are impaired not only in their ability to engage in typical pretend play (which was the basis for the Wing and Gould’s notion of impaired imagination in autism) but also in their ability to form mental images and draw pictures of impossible objects.

However, many clinicians have suggested the opposite. For example, in his original account, Asperger (1944/1991) noted that autistic children have “high level of original thought” and good imaginative abilities (p. 37). Thus, one of the children Asperger described, Harro L., created “long, fantastic stories” (p. 51) as did other autistic individuals described in other clinical

16 Note Pierre’s sense of humor here.
accounts (e.g., Bölte & Bosch, 2004; Bosch, 1962/1970; Sperry, 1995). Arguing against Wing and Gould’s (1979) view of autism in terms of impaired imagination, Tantam (1991) maintained that autistic individuals are “not always deficient in imagination” (p. 179) whereas Attwood (1998), writing about individuals diagnosed with Asperger syndrome specifically, wrote that they have an “original way of thinking” and “good imagination” (p. 179). Moreover, Attwood (2006) included “original ideas” (p. 46) as one of the strengths of individuals diagnosed with Asperger syndrome. Likewise, my own analysis of the spontaneous creations of autistic individuals documented in clinical, biographical, and autobiographical accounts showed high imaginative abilities in areas such as drawings (of imaginary objects and places), fiction stories, poetry, and descriptions of imaginary friends and other beings, worlds, places, objects, as well as daydreams in which autistic individuals imagine themselves doing things they have not done before, being in faraway lands, or places they have never visited (Vuletic & Ferrari, 2006). Pierre’s imaginativeness then adds to this body of evidence to include the ability to mentally create possible worlds that do not necessarily revolve around the self as previously suggested and discussed as “escape into imagination” (Attwood, 2006, p. 24).

9.3.1.1.2.1 Other Participants

No other participants in this study defined themselves with a reference to their imagination or future-orientated thinking like Pierre did. However, based on the interview data, and participants’ visions of their futures in particular, it does not appear that any other participant had particularly strong imaginative abilities like Pierre claimed to have. Likewise, although some of the participants had more elaborate visions of their futures than the others (which I review later), none showed a lack of ability to think about the future. However, although Alan was able to share his plans for the future, he appeared somewhat uncomfortable talking about hypothetical situations, suggesting that “It’s impossible to know for sure,” and he did not seem to appreciate my suggestions that I am interested in what he believed was possible, not in what is really going to happen.

9.3.1.1.3 On Pierre as Anti-Social
Pierre described himself as “anti-social—maybe.” From his explanation of why he believed that he is anti-social (he does not have a lot of friends and stays home a lot) and his other comments (e.g., “it takes me a little while to get friendly with people, that’s connected to my being anti-social”), it is obvious that Pierre uses the term anti-social in a colloquial (i.e., a-social, or not very social) rather than in a psychiatric sense (i.e., behaving against the well-being of others; APA, 2004; R. Blackburn, 2007). Therefore, to avoid confusion, in the reminder of this thesis, I will use the term asocial instead of anti-social when talking about Pierre’s and other participants’ social styles and/or difficulties. Because Pierre was not entirely convinced that this attribute properly described him, as his inclusion of maybe suggests, and because there is other evidence that supports his indecisiveness about it, I refer to his and, when applicable, other participants’ global social characteristics as a/socialness. (When referring to instances of clearly expressed social difficulties, I use the term asocialness.) To consider support for Pierre’s self-defined a/socialness, I review and discuss what he said during the interview, what I observed both during and outside the interviews, and what he wrote in his diaries.

What Pierre said. Although Pierre said that he has several friends, he spends relatively little time with them: He sees his two best friends (a couple) several times a year, only chats with the third one during their relatively short ride home after the choir rehearsal, and talks with the fourth one only occasionally and only about politics. Instead, he spends his days predominately in solitary activities including spending around 7 hours a day reading, watching DVDs, and solving puzzles. Pierre never talked about his need or wish for friends when he was younger although, based on his answers in the follow-up interview, it appears that he did not have any friends until he met the couple who are now his best friends (whom he met through his sister 15 years ago and who are also her friends). Thus, when asked whether he can remember his first friend, he replied, “Not at the moment,” and when asked whether he believes that it is possible that he had other friends before the current ones, his reply was, “Well, I’d have to think about it.” However, Pierre now wishes to have friends and is currently actively perusing finding them through Meetup groups (about which he talked enthusiastically in both the interview and the diaries). Pierre also said that he enjoys many social activities such as singing with or for others and participating in community projects. This mix of evidence for both socialness and asocialness clearly supports Pierre’s use of maybe when he described himself as an a/social person.
When describing his social difficulties, Pierre said that he finds it “hard to be casual” and to “loosen up.” He finds small talk particularly challenging and questions such as *How are you?* difficult to answer because, “on one level” he does not know how he is. He also said that he lacks self-presentation skills with regard to dating. Although these difficulties support Pierre’s asocialness claim, there are many other indicators that justify Pierre’s tentativeness about it (the “maybe” part). For example, Pierre believes that those who know him well, such as his family, would describe him as a *caring* person because he considers other people’s problems as if they were his. If true, this certainly does not fit well with an asocial person. Pierre’s diaries provide some support for this suggestion. For example, he once made a comment that he discussed his father’s health problem with his “Internet friends,” and that they had advice for his father (July 4, 2003). He also expressed a concern for his mother’s health with regard to her ability to travel to another city with him and his father for a summer theater festival (2008; I did not record the date).

*What I observed.* I met Pierre eight times, each time confirming the previously formed impression of a person with a highly delicate blend of *socialness* and *asocialness*. Each time, the first and last impressions were clearly of an asocial person as none of our meetings contained usual greeting and parting rituals. Not only did Pierre feel uncomfortable with answering *How are you?* questions, he also never followed them up with the “standard” *Thanks, how are you?* However, once we started talking, usually about the book he was reading (he always came before me to our meetings and was always reading when I came) or, on two occasions, about the performance in which he participated, the conversation proceeded very smoothly, if not exceptionally smoothly. Pierre met all my questions with a lot of enthusiasm, and he talked passionately about the books, their authors, their other good books (if I did not read them), about the performances, and would appropriately ask me a number of related questions. He did not talk too much, nor too little, just enough to convey the most important and most interesting points which often included some humorous bits. Pierre also seemed comfortable with introducing related topics into a conversation, even occasionally venturing into unrelated topics (e.g., my experience with my supervisor and the political situation in the country of my origin), and he did not seem to have *any* conversational difficulties—at least *not verbal ones*. Therefore, Pierre’s “performance” in what he considered the most challenging aspect of social interactions, also seems to support his tentativeness about his a/socialness: He was doing both well and not so well
in it, depending on the phase of interaction—from my perspective. However, I am not sure how much Pierre was aware of his greeting and parting omissions, nor whether he considers them important.

As I already mentioned in the introductory description of Pierre, he only rarely made eye contact during our conversations, both during and outside the interview situation—although he did much better outside the interview. However, Pierre never mentioned eye contact as his difficulty. Moreover, when I asked him about it during the follow-up interview, he said, “I think for me it isn’t particularly uncomfortable, just I don’t do it naturally. I have to make a decision to do it, like I am doing now [looking at me and smiling].” From this perspective, it is understandable why Pierre does not see his eye contact as a problem. However, he also acknowledged that other people, such as instructors at the job training agency, found his eye contact problematic. Although he also admitted that “it’s an important skill to develop,” he did not appreciate it when the instructors told him about it, and “felt they were [micromanagers], a bit.” (As Pierre very patently explained it to me in the follow-up interview, micromanagers are those who insist on rules for which “there is no real reason.” He further explained, “Like some people think, “Is this advice important enough for me to give. Micromanagers, they don’t ask that question, they just automatically assume it’s important. Micromanagers, they don’t so much have that balance mechanism.”) Although I personally do not find eye contact particularly important, I believe that it is fair to say that from the third-person perspective, Pierre’s conspicuously absent eye contact (when other people would expect it, as opposed to when Pierre makes a decision to make it), provides clear support for his asocialness.

Nevertheless, Pierre also demonstrated his socialness in his fine attunement to my perspective as well as to my nonverbal cues. Here is an example. In the follow-up interview, I wanted to clarify one of Pierre’s answers involving the word micromanager. After answering my question, and after I paused, Pierre asked me, “Do you want me to explain some more about micromanaging?” That was exactly what I was about to ask him because I did not quite understand what he meant by it. He responded to my emphatic “Oh, please do!” by saying:

It’s like, let me give you an example, like, you know, in a WW2, there was a lot rationing, and, like, in Brittan they rationed meat and sugar and such, but they also rationed marmalade. And I was thinking, “Why did they have to ration that?” Seems to
me, “Marmalade isn’t important enough. If people run out of marmalade, who cares?” And I was thinking, “They were rationing just for the sake of rationing as much as they could.” That’s what I mean by micromanaging, I guess.

There was a big pause as I still did not see how this example applies to the situation we discussed. Pierre realized this and gave me another example, closer to my life experiences, communism in Yugoslavia. I still did not understand, and Pierre correctly interpreted my vague reply as not understanding and proceeded to make a comparison of micromanagers and not micromanagers (as quoted in the most recent footnote), but after my subsequent questions showed him that I still did not understand the gist of micromanaging, he gave another example. I replied unconvincingly, “Okay. [pause] I see,” which Pierre again, quite appropriately, interpreted as still not understanding and proceeded to extract the gist from his example (“there is no real reason”) that I finally understood. I was not aware of the level of Pierre’s responsiveness to my nonverbal clues during the conversation itself, and was very surprised by it when I listened to the tape (as I was surprised by my not understanding!). Once again, I had witnessed Pierre’s socialness in its finest form. This example, once again, testifies to the true complexity of Pierre’s a/socialness.

**What Pierre wrote in his diaries.** On the face of it, Pierre’s diaries seem to unequivocally lay bare his asocialness: an overwhelming majority of entries involve his solitary activities (reading, going on the Internet, watching TV, DVDs, solving puzzles, and going to the movies, library, book- or video-store). In addition, the content of some of the entries testifies to his preference for being alone. For example, when his sister and her family come for a visit, he does not seem to particularly enjoy their company and usually seems annoyed by them. Thus, when they came for the weekend over Christmas holidays in 2007, he wrote, “I can’t think straight when we have company” (December 29). Similarly, after they left following spending the weekend together during Christmas holidays in 2003, he wrote, “[Sister] and her brood finally returned to [Hamilton]” (December 29). Perhaps even more revealing of the depth of his preference to be alone is his entry for a New Year eve in 2007: “Then I went out to [Jerry’s] New Year Eve party at his apartment on [Front] Street. I only stayed for an hour. / I took a sleeping pill so I’d be asleep by midnight” (December 31, 2007).
However, Pierre’s diaries also contain many entries involving his social activates (most weeks there would be at least one such entry, usually related to his community engagements—choir practices and other community projects—Meetup groups, and, occasionally, two best friends he mentioned during the interview), thus confirming the “maybe not” part of Pierre’s self-defined a/socialness. Yet, the content of these entries may also be taken as evidence of the other, “maybe yes,” part of his a/socialness: Pierre never included any reference to his subjective feelings, such as enjoyment of these activities, as we might assume somebody who is not asocial would at least occasionally do. Indeed, like the entry for the New Year Eve party, Pierre’s diary entries rarely include anything beyond minimal facts about the activity. It seems as though Pierre did not need, or want, to write about the reason(s) why he left the party only after 1 hour and what his thoughts and feelings were (either during the party or when he got home and took sleeping pills). This factual treatment of his social experiences applies even to his much talked about socializing in Meetup gatherings. Here are several of these entries:

Went to [Oscars] Meetup at [Danny’s] near [Lawrence] station. Four women showed up, with only one cancellation!” (February 17, 2008)

Went to the [Oscars] Meetup at the [Big Bear] Cafe. (There were five people there.) I had the mini waffle special of four mini waffles, two with poached eggs, one with ham and cheese and one with fruit. It was quite good. (April 6, 2008)

Had [Oscars] Meetup at [Cafe Pi]. There were five people including a new Korean couple. I had scrambled eggs with very spicy sausages. (June 22, 2008)

Descriptions of his get-togethers with his two best friends are not much different:

[Joan] and [John] came over for dinner which was Indian butter chicken and some other stuff.

We saw the DVD of the first episodes of the second season of The Bob Newhart Show. The therapy group is really funny! (January 12, 2008)

[Joan] and [John] invited me over for dinner. We ate spaghetti. (March 30, 2008)

[Joan] and [John] invited [his sister] and me over for dinner which was spaghetti. We looked at The East Is Red [original underlining], a Chinese propaganda opera-ballet from the early ’60s. (I noted [John reading an updated version of How to Prosper in the Coming Bad Years [original underlining]].) (May 27, 2008)
Meetings with people he did not see for a long time (for example, a woman he met while he was researching for his PhD thesis abroad) are entered in a remarkably similar way: “Met Miss Edwards (Warden of Trinity College when I was a resident there) at lunch time. Lunch was linguini with meatballs” (March 16, 2004). Meeting people for the first time, like meeting with me for the interview, is entered: “Ljilianna [sic] interviewed me in the OISE building on the U. of T. campus as part of her Ph.D. research. (Her first language is Serbian!) I’m meeting her next week too” (June 16, 2008). His entries regarding his encounters with his psychiatrist merely recorded just this much, (but note his comment on what he was reading on his way to the meeting): “Went to Dr. [Ross]. (On the way there, I read some more of The Encyclopedia of Bad Taste [original underlining]. Very illuminating!” (January 4, 2008). Several exceptions include occasional entries indicating that Pierre discussed his diaries with his psychiatrist that he suggested he read a particular book, and why, and that the psychiatrist made a note about his diagnosis. Here is one such entry: “Afterward I went to Dr. [Ross] and he wrote a note confirming my Asperger’s diagnosis for Ljilianna’s [sic] records. (I got caught in the rain.)” (June 16, 2008). Finally, entries about family reunions are recorded in the same fashion: “[His brother], [his brother’s girlfriend] and [his other brother] came for Thanksgiving dinner, which was Indian food” (October 8, 2007).

When considering Pierre’s diary evidence it is important to know that although there are many ways to keep a diary, the usual way people do it involves reflecting on one’s thoughts and feelings about the recorded events and the people involved. According to the Canadian Oxford Dictionary (Barber, 2004), a diary is “a daily written record of events, feelings, or thoughts.” Or, as Lejeune (2009) put it, in a diary “you write whatever you’re doing, thinking and feeling” (p. 168). L. Woolf made a similar remark in his preface to Virginia Woolf’s Writer’s Diary (1953); he wrote, “the normal way of diarists [is] to record what [they] did and what [they] thought about people, life, and the universe” (p. viii). Nevertheless, in his study of diarists’ writing habits, Lejeune found that diarists differ widely in what they record. He suggested that there are three main types of diaries: (a) chronicle of events, (b) truly personal diary, and (c) spiritual journal.

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17 Note that these entries are similar to Pierre’s entries about the tasks and chores he undertook. Consider, for example, his shopping entry: “Afterwards I went to Loblaw’s to get multigrain flour. I also ended up buying grapefruit (they have nice big ones there), Pepsi and a strawberry cake. It cost over $30” (June 10, 2008).
Clearly then, Pierre’s diaries should be classified as a chronicle of events, or “factual chronicle” (p. 34).

It is also important to know that Pierre started keeping a diary because his psychiatrist recommended it. However, because the only instruction as to what to write that Pierre remembers concerns recording his dreams, which Pierre diligently recorded as the first entry every day (in the first two diaries, but got more flexible with it in the last diary), it seems safe to conclude that choosing a chronicle type of a diary was Pierre’s choice. And although it is tempting to assume that it is very likely that a psychiatrist would suggest recording one’s thoughts and feelings in a diary, Pierre gave no evidence that this was the case with his psychiatrist. Moreover, given that Pierre noted several times in his diaries that he discussed the diaries with his psychiatrist, without any subsequent change in his diary style, it seems safe to suggest that Pierre’s psychiatrist was happy with Pierre’s chronicle, rather than a more intimate, approach to diary keeping. In fact, one of his early entries reads: “Brought the diary to Dr. [Ross]. It’s a big breakthrough. (My dreams impress him.) He’d also like me to look into [illegible] crossword puzzles.” (March 11, 2003). Next month, he only wrote, “Brought Dr. [Ross] my February entries” (April 2, 2003).

It is then not surprising that as a historian Pierre is more concerned with recording factual than subjective aspects of his life. As any good historian would, he recorded facts: who (or how many), where, and what, and he (usually) put his occasional subjective views of these facts in parentheses (as a historian perhaps would in a historical chronicle). (However, Pierre did not follow this approach with regard to his entries about the books he had read, and the films and art and museum exhibits he had seen.) This approach to diary writing makes Pierre’s diary entries look like objective historical descriptions of his life. However, some might argue that even for a historian, it would be unusual omitting mentioning something about the people involved. Even Samuel Pepys (1970), one of the earliest and the most famous diarist of the 17th century—whose diaries Pierre had read and introduced to me—recorded his observations about people he met. (In the words of Virginia Woolf (1986), Pepys’s descriptions of social events are so “graphic” that they let us “latecomers . . . still [be] in time to make one of the party”; p. 235.) In fact—and curiously enough—Pierre said that he particularly liked Pepys’ descriptions of people! (It should be noted that several autobiographies of autistic individuals that include excerpts from their
diaries (e.g., Grandin & Scariano, 1986; Grandin, 1995c; N. Jackson, 2002; Prince-Hughes, 2004) clearly show that “factual chronicle” is not a type of diary that is preferred by autistic individuals as these excerpts look like being taken from “truly personal diaries” in which diarists wrote about their thoughts and feelings about themselves, other people, events, and universe.

Pierre’s omission in including his subjective evaluations (i.e., his thoughts and feelings) of social events and their participants seems even more surprising when we consider that, in the above excerpts, he departed from his “objective” historical approach when he commented about the food (“quite good” and “spicy”), TV show (“really funny!”), and the book he was reading on his way to his meeting with his psychiatrist (“Very illuminating!”). Indeed, Pierre’s more personal treatment of his non-social experiences against his strictly historical treatment of his social experiences is perhaps one of the most salient features of his diaries, as well as a potential indicator of his asocialness. Thus, while, on the one hand, Pierre rarely omitted making a comment on what he read or saw, on the other hand, only rarely did he make evaluative comments about his interpersonal experiences. Of course, this differential treatment of human vs. nonhuman environment is an essential feature of autism noted by both Kanner (1943) and Asperger (1944/1991; see also Attwood, 1998, 2006).

It is important to note that Pierre’s comments are usually very short (as are ones cited above). For example, comments about books, films, and gallery and museum exhibits usually consist of clichés and general remarks such as “enjoyable,” “marvelous,” “pretty funny,” “magnificent book,” “terrific story,” “great acting; great scenery,” “very imaginative,” “too much narration,” “It’s a really great book, with a better plot than Harry Potter,” “It’s terrific movie, exciting and intelligent and believable. Lots of ‘How did they film that?’ shots,” “I like those Camille Pisarro landscapes,” and “I liked the dioramas recreating scenes from the history of medicine.”

From such a differential treatment of his social and non-social experiences, it is possible to speculate that perhaps Pierre does not engage in an intellectual and/or emotional processing of his social experiences. One could argue that if he made a comment about something, as in case of The Encyclopedia of Bad Taste, it probably means that he had an emotional and/or intellectual reaction to it, and, by logical extension, if he did not make a comment, as in case of a meeting
with a psychiatrist, that it probably means that he did not have such a reaction. A partial support for
this interpretation could be found in his occasional entries in which he reflected on his social
encounters that evoked negative (with one exception) thoughts and/or feelings. For example,
several 2003 diary entries contain his thoughts and feelings about his experiences with people
from the employment agency that he mentioned in the interview (and through which he obtained
his only employment). The first such entry reads, “Still worrying about meeting the [TFC]
people” (January 6, 2003). Note that he did not say why he worried. However, according to
Lejeune (2009), this is nothing unusual because unlike autobiographies, diaries are usually
written for oneself, and diarists have their ways of filling in the blanks. As he put it,

The diary is a piece of lacework or a spider web. It is apparently made up of more empty
space than filled space. But for the person who is writing, the discrete points of reference
that I [sic] set down on paper hold an invisible galaxy of other memories in suspension
around them. (p. 181)

Two days later, after Pierre wrote that he “finally called” the agency and made an appointment,
he commented, “I’ll be glad to have it over with” (January 8, 2003). (When I asked Pierre in the
follow-up interview about the “problem” behind these entries, he said that he felt that the
instructors were “micromanagers.”) Finally, after the appointment two days later, he had more to
say:

Went to the [TFC] meeting and told them I didn’t want to continue. It was like getting a
tooth pulled. [Sam], I know you can’t quit school just because you don’t have the right
chemistry with your teacher. But I’m a grownup so it’s my responsibility. (January 10,
2003)

Ten days later, Pierre revisited his experience with the TFC: “I still feel bad about my departure
from [TFC]. At least my family all think I made the right decision” (January 20, 2003). (Note
that several months later Pierre went to the agency again and “got back into it” (June 11, 2003).
The only other entries with a more personal treatment of his interpersonal experiences in that
year are related to a conflict at the dance studio party:

Was dancing with [Anna] and she said something that hurt my feelings. [Maria—
instructor who was often mentioned in the 2003 diary] comforted me afterwards. I told
her she’s a really kind person. I wish I could do something for her. (June 20, 2003)
Note that in the above entry, in addition to a negative reaction to Anna’s comment, Pierre also recorded his positive thoughts about Maria. Also note that there was another entry from the same year, which was not very legible but which Pierre read to me, in which Pierre commented about Maria’s looks and talents and in which he recorded his daydream about being a millionaire and giving his money to Maria, which is the only daydream he recorded in the diaries that I had read. The following day, one of his entries read, “I’m still sown about being criticized at the dance party” (June 21, 2003).

Although these are the only entries for 2003 in which Pierre commented on his interpersonal experiences, they clearly demonstrate (among other things) (a) that he does get emotionally affected by his social encounters and (b) that he can write about these experiences. Interestingly, there were no such entries at all in his 2004 diary. However, his 2007/8 diary again contains several personal entries, two of which involving his two sisters. The first entry:

[Jane] [oldest sister] and her family visited briefly on their way to soccer game / Dinner was churrasco chicken, as usual when they come. She started bugging me about showing my last name in my Meetup file, and I got very annoyed. I’m actually not sure if I do that, but it’s none of her beeswax! At least we didn’t quite have a scene. (December 5, 2007)

The second entry is probably the most personal revelation included in any of his diary entries, and it also contains a rare mention of his mother:

In the morning I carelessly mentioned to [Mary] [sister who lives in the same house] that I was going to sing at a Meetup today and she gave me a lot of trouble. She went on about how [ST] voice is annoying. (Is she saying my voice is annoying too?) At times like this I wish I lived anywhere else! It’s important to me to have a life in the outside world and I resent it when other people in the family make it their business. (Mother was giving me trouble too.) (July 5, 2007)

The final entry that included his personal reaction to an interpersonal event involved a conflict in one of his Meetup meetings:

I had words with [Susan] [group organizer], and now I’m quitting. (I didn’t stay to talk about [Leaf’s last game] [Meetup topic].) The bottom line is that in addition to [Hockey] Meetup, she also has to have [Basketball] Meetup, and is too rigid to [change the schedule]. Hard feelings. (I hate losing friends!) (December 11, 2007)
These entries, although not as numerous as one would expect for a stretch of 3 years, clearly show that Pierre can put his thoughts and feelings on paper when they are significant enough and provide support for the interpretation that failure in mentioning them could mean their absence. Taking this idea one step further, one could argue that Pierre’s socializing could be a result of a conscious decision to spend more time with people (for whatever reason), but that he does not derive much personal satisfaction from it, or at least not as much as he derives from reading, solving puzzles, and other solitary activities. However, as L. Woolf (1953) reminds us, we should be careful when imputing psychological characteristics to diary writers based on diary entries alone:

Diaries give a distorted or one-sided portrait of the writer, because, as Virginia Woolf herself remarks somewhere in these diaries, one gets into the habit of recording one particular kind of mood—irritation or misery, say—and of not writing one’s diary when one is feeling the opposite. The portrait is therefore from the start unbalanced. (vii–viii)

Lejeune (2009) agrees and writes that “a diary is rarely a self-portrait, or if it is taken as one, it sometimes seems like a caricature” (p. 179). Mindful of these cautionary notes and in light of the psychological literature on depression, according to which depressed and depression-prone people show information processing bias toward negative experiences (Mathews & MacLeod, 2005), we have to give a benefit of doubt to any interpretation of Pierre’s true thoughts and feelings about others based on diary entries alone. In addition, in light of autobiographical literature of autistic individuals, interpreting absences in diaries as absences from real life may be unfair to Pierre because many autistic individuals talk about a prolonged period of time they need to “apprehend” people (e.g., J. Blackburn, Gottschewski, George, & Niki, 2000; Grandin, 1995c; Prince-Hughes, 2002).

**Putting all evidence together.** Although in the interview Pierre emphasized his recent efforts to socialize more, which certainly make him less asocial than before, from an outside perspective (informed by his interview, my observations, and his diary entries in particular), it is reasonable to suggest that many people would, without any doubt, still consider Pierre a rather asocial person. First, Pierre never talked about feeling lonely, neither in the past nor currently. In fact, the way he talked and wrote about his socializing efforts more resembles an item from the to do list (find a job and a girlfriend), than something he does because of his need for affiliation or
affection. Second, from Pierre’s diaries, in which he wrote about being in the same space with others but not about being with others (that is, about his thoughts and feelings about the experience), it is not unreasonable to suggest that social encounters do not appear to have the same—social and emotional—meaning for Pierre as they do for most other people. Yet, however different the meaning that Pierre made of his social experiences might be from that of others’, it is possible that this meaning might also be somehow different from the meaning he makes of his non-social experiences, but that he is just not able, or willing, to express it. In other words, it is still possible that Pierre does engage in an intellectual and/or emotional processing of his social experiences after he had them, but that he does not have a need to write or talk about what he thought or felt. For this reason, and considering Pierre’s existing relationships, his significant efforts at improvements (regardless the reason), and my good impression of his conversational skills, I conclude that Pierre’s inclusion of the maybe part in his self-defined a/socialness was justified.

Moreover, from a broader perspective (one independent of psychiatric thinking), one could argue that there are many ways to be social. Temple Grandin, for example, does not consider herself asocial despite the fact that her social life is not built around emotional connections with people, but around her business and career. As she stated, “Almost all my social contacts are with livestock people or people interested in autism” (1992, p. 123). So if Pierre had a career where he could spend a lot of his time working instead of being involved in leisure activities for most of the day, and if he had colleagues with whom he could exchange ideas, perhaps he would not think that he is asocial despite having all the other signs that point to asocialness from the outside. His care for others and his excellent reciprocal conversational skills, his fine attunement into perspectives of others, as well as into the nonverbal clues, which contradict the common view of autistic individuals’ lack of ability to read nonverbal clues, and to be attuned, or even care about others’ perspectives, demonstrate both the multidimensionality of autistic individuals’ a/socialness, and provide excellent grounds for his future social development.

9.3.1.1.3.1 Other Participants

9.3.1.1.3.1.1 Orville
Like Pierre, Orville, who also has several casual friends but not a romantic partner, described himself as an asocial person, referring to himself as a “loner.” However, in contrast to Pierre, who included his a/socialness as his third defining characteristic, *loner* was Orville’s first response to my request for a self-definition, which, perhaps, indicates a higher level of importance. Indeed, Orville’s whole interview is, for the most part, just an elaboration on the a/socialness theme. Consequently, Orville’s account of his a/socialness is much more elaborate than Pierre’s. For example, it includes his whole history of a/socialness, which he spontaneously provided in response to a request to define himself:

> [The] only word [that] comes to mind quickly is loner. All my life I’ve been more or less loner person. At school, I would go out at recess to the edge of the schoolyard, sit there, stare at the trees, and I didn’t want to take part in any sports, and I didn’t wanna chitchat with others, and I just couldn’t understand why even one person from the school yard didn’t wanna come and sit beside me just to enjoy the perspective of the trees against the sky. [. . .] And the same in high school, although some of the students became more . . . “bullying” and “belligerent” . . . in high school than they were [in] elementary school as though I was a man, as though I was supposed to be doing what everyone else [was], [be] a football hero and all that stuff, and I had no interest at all in that, and I just I couldn’t seem to relate to others. I’d see other people going together and that . . . I just was totally lost as how to approach anybody. [. . .] Even [on] weekends, I just wanna go out in the woods by myself alone, and hike, and explore the streams and that, and just wasn’t interested in going to any parties, or do’s, or stuff like that. [exhales loudly]

However, although both Pierre and Orville described themselves in terms of asocialness, for which they both provided ample evidence, both of them also presented evidence for their socialness. Yet, in contrast to Pierre, who never explicitly expressed his need for friendships during his school years, and which is only occasionally implicit in his interview, Orville explicitly expressed his need many times throughout the interview. For example, he said that he “would’ve liked it very much” if a boy or a girl wanted to go with him and explore the streams and hike in the woods. His problem was that nobody wanted to do that, and he was not interested in what interested them. Therefore, his early preference for aloneness seems to be one of necessity, rather than a genuine liking for being alone, which, more likely, seems to be the case in Pierre’s early life. As Orville put it:

> When I was [in] elementary school there, I was looking at this beautiful horizon before me, and the trees, and the clouds, and yet, I just had nobody to share it with [. . .] I just wanted a partner to share this experience with me. And I feel the same today [. . . .] But again, it would have to be a partner that does understand these things about nature, and
not somebody who would constantly be nagging at me to go and join them, say [a] cricket league or something else like that. [chuckles]

In fact, Orville’s whole account revolves around his need to bond with other people. Two of his other statements on that theme may be sufficient to illustrate this observation: “The only thing [that] seem[s] to be missing is that other partner to share this life with” and “Life is wonderful, but the partner’s not.”

Also in contrast to Pierre, who never compared his social skills to those of others, Orville did it many times. This comparison led him to believe that his asocialness comes from his inability to relate to others. That is, “getting friendly with people” for him was not a matter of time, as Pierre suggested, but rather a matter of ability which he believed he did not have. He referred to his main problem as “lack of being able to connect and bond with other individuals,” and he attempted to explain it many times during the interview. For example, on one occasion, he said:

I’ve attended meetings so much of my life, and I can relate to people around tables and that, but then [when] the meeting’s over and I’d go home, I feel still isolated—I haven’t connected or bonded with anybody. And I keep asking people all my life, “Oh, how does a relationship with others develop?” And I see even teenagers . . . all of a sudden there’s a guy walking with a girl or something or whatever, and I ask myself, How did that happen? People tell me it just happened to them, and I keep asking, “But why hasn’t it just happened to me all these years?” and nobody, even these professionals don’t have an answer. The other characteristic is there just doesn’t seem to be any information, if you call it that, or instinct even, to connect with another person on a more closer, personal level—beyond the board-meeting level—[chuckles] and be able to discuss personal issues to the point of them wanting to relate closer that way.

On another occasion—when describing his second weakness—Orville reiterated his points as follows:

When I’ve been in these groups—usually after the meeting’s over, before people leave and that—where I try to communicate . . . somebody might be very short, and the next I see this person talking to somebody else, and boy, it’s almost as I stand there, they seem to be almost bonding with each other and talking about things that I would almost consider private, almost like they’re getting into a private discussion and moving away from me and the rest of the group. And I’m thinking, What on earth is making them begin to bond together? How do I do that?
In contrast to Pierre, who never suggested that he was seriously affected by his asocialness, Orville maintained that his social inability, which—before he was diagnosed with autism—termed *chronic social learning disability* prevented him from meeting his social, as well as biological, needs. In his response to the question what he likes least about himself, he described his “lack of being able to communicate in the intimate sense with people”:

[When] I was growing up, I just couldn’t communicate. So there I was living—what’s that word—celibate, all those years as though I was more celibate than the priest could ever tried to be. [There was] just no connection that way, intimately, with person of the opposite sex. I just didn’t know how to do it, and [it] was going to all . . . through my twenties and to my thirties and even when I was 24, [I] was talking to my dad about this. [. . .] And [. . .] I talked to my sisters about it [. . .] And then through my thirties into my forties, and then it’s when I . . . it was in my late forties [. . .] when I felt, There had to be something for it, so I even had to come up with my own term for it—even before any of these diagnoses or even hints about what it was—I came up with the term “chronic social learning disability,” is the term I came up for it. [chuckles] I just couldn’t seem to socially connect with other people. And there was this intimacy that my body needed to complete its biological urges, but I just had no sense of going out and . . . feeling as though I had to rape a woman or something like that to satisfy my urges or anything like that. I never did even approach anybody like that, but still it was there, and I didn’t know how to answer it, and that.

The lack of success in bonding with others, despite all his efforts, made Orville feel as if there was an invisible barrier between him and others—as if he were living “in a bubble”:

No matter how much I try to connect with others, it’s a feel like I’m in a bubble, almost, and I’m trying to reach out, but almost, like this bubble around me is preventing me from connecting to others—it’s what it feels like.

Notwithstanding these differences, Pierre and Orville’s accounts were similar in that they both found small talk a very challenging task. In fact, Orville considered his lack of understanding it his main weakness. He said that small talk or, as he calls it, *chitchat*, is “like a foreign language” to him and that he cannot apply it even though he knows some of its rules and vocabulary because he does not have a “deeper understanding” of it:

I can’t . . . get the understanding of what I would call everyday chitchat into what my deeper understanding of human nature is about. When somebody brings up the weather, “Oh, how was the weather weekend [sic]?” and “How did your weekend go? Did you have a good trip?” and I’m asking myself, But what does all this mean? Why are these people communicating this way? What are they really trying to say to each other? It’s
almost like they don’t know how to say really what’s on their mind so they have to come up with this superficial language, is what it sounds like to me. And when they talk that way even to me, I’m trying to figure out in my mind, really, What is the person trying to tell me directly? And because I’m trying to figure that out, maybe, that’s what makes those people say, “Well, nice chatting with you, I have to be going.” [chuckles] That would be what I would consider weakness. Now, whether somebody else might consider [it] a strength is a debatable thing.

From a third-person perspective, Orville’s insistence on understanding the deeper meaning of something that does not have any such meaning, as his reference to it as a “superficial language” suggests he too understands, may seem strange. Moreover, his implicit insistence on the rightness and superiority of his perspective on the issue with which he has difficulties (which could be summed as, any communication without a deep meaning is worthless) also seems to interfere with his attempts to establish social relationships. However, from Orville’s perspective, the problem is much deeper than this. To him, it “almost feels terrifying” when he feels pressured to apply the rules he only knows by rote and does not know where they “might lead to”:

I think I could learn [to chitchat] as long as I am not told [. . .] to go along with what they call the pretense, so that you have to pretend this is going on even if [you] don’t feel it that way as part of the process and everything. [. . .] Even if you don’t feel it instinctively, you have to pretend to do it this way. I just don’t feel as though I can pretend at all. As though I have to be the person I am, and I’d like to find somebody else who is willing to accept me the way I am without me pretending to be normal some way [chuckles], is what I keep trying to tell people if other people say, “Well, here, make better eye contact, here, smile when you meet a person, be willing to ask them, “How was your day?” and that. And I say to myself, Well, maybe [that’s] the way normal people chitchat with each other, but it sounds like a foreign language to me. And I just don’t feel that’s part of me, part of system, as though it’s me going into a jungle, and they are practicing this [rule of] dance or something and are asking me to dance with them, and I don’t even know what the dance is about [chuckles] or anything, is what it feels like [chuckles], and they’re telling me, “Get up there and dance with everybody anyway—you’ll find out later what it’s about.” And yet [it] almost feels terrifying to me, in a way, [chuckles] cause I don’t know what it might lead to.

Although this perspective may not be completely explanatory of Pierre’s unwillingness to accept others’ suggestions to “make better eye contact,” as Orville put it, it does seem to shed at least some light on why Pierre considered such suggestions micromanaging (i.e., without a “real reason”). Thus, from Orville’s perspective, we can clearly see that what from the outside may look like Pierre and Orville’s counterproductive and automatic defensiveness, may in fact be
their conscious choices stemming from their deep beliefs in their “goodness” as they are and from their value system according to which there is no “real reason” to change things that are unimportant—in this case, appear like everybody else. As Pierre was patiently trying to explain to me with his if people run out of marmalade, who cares? example, Orville also seems to have suggested, “who cares about changes that do not lead to becoming a better person? Let’s care about what we say and what we do.” Indeed, when others tell Orville that he needs to change, it sends him the wrong message, that he is not good enough as he is and that, unless he changes, he will not be accepted. As Orville revealed, such messages made him be “almost afraid to approach people.” Moreover, he revealed that for him not being accepted by others is a lesser evil than not being accepted by himself and that if he changed things about him that others wanted him to change, he would not be the same person and would feel alienated from himself. And that is something he cannot accept. Although Pierre did not say that, I think that what he did say is consistent with how Orville felt.

9.3.1.1.3.1.2 Mike

Although the main topic of Mike’s whole interview was his asocialness, in the sense of having difficulties in establishing relationships—as reflected in many of his statements such as “I had always difficult time socially,” “Establishing relationships in general, I don’t do well,” and “I have a difficulty with trying to establish new relationships”—he never referred to his social difficulties as his self-defining feature. Instead, as his second self-defining feature, he referred to where these difficulties led him in his effort to overcome them—to “try[ing] to be good to people.” But before I discuss these efforts, I introduce Mike’s social difficulties, which he considered his main weakness and described forcefully as, “I really bite at relationships. I am really terrible at relationships—really terrible at it. I want to basically love and be loved, but I just don’t.”

Mike’s social difficulties appear to be the most complex of all participants’ as he was the only participant who was both married and had a job that required a lot of social contact, thus experiencing his social weaknesses in many different contexts and at different levels and stages of relationships. Although when he was younger, he said he “was more of an isolationist,” it was
not because he did not like people, or did not want to be with them, but because real “bonding,”
to use Orville’s word, just never happened:

But I did like to hang out with kids, but I would never hang out with them very much. I
did spend a lot of time by myself, but I did like people, I know that. And I did hang out
with kids in my neighborhood and drive around on bikes, but . . . And then when I
became a teenager, yeah, I had friends then too but . . . not as many as other kids did. It
never . . . you know what I mean? Not . . . nothing that was life long, that lasted, you
know what I mean?

As already mentioned, currently, Mike does not have any close friends despite his intense
longing for them: “I don’t have any friends. I don’t. I have no friends—none.” This makes Mike
long for any kind of friendship, with “guys and girls,” “women and men,” with anybody who
will “call me up, and I’ll say, ‘Hey!’” [and they’ll say:] ‘Hey, you wanna head out and have a
coffee? John, and Barb, and Barbara [are] coming over. Hey, do you wanna come out for a
coffee?’ Stuff like that.” Mike expressed his deep-felt need for friendships many times during the
interview. Indeed, his intense desire for close relationships was the most prominent theme in the
interview. It is perhaps best expressed in his statement about his future: “I would like to meet
friends—I would like to meet lots of friends.” Likewise, the depth of his desire is best illustrated
in his reply to a question “If you could choose to be any kind of person, what kind of person
would you want to be?” to which he replied, “A person with a lot of friends.”

Not only does Mike wish to have friends, he has also been trying for years to establish
friendships, and as already mentioned, in that effort he “try[s] to be good to people,” which he
elaborated as follows:

I try to make people want to like me, and I try, you know, naturally, but I want people to
like me, basically, as a friend and stuff like that, but like I say again, everything is
professional, mainly . . . has something [to] do with professional contacts, whatever. It
never really develops into anything long term, you know what I mean?

Mike’s efforts “to be good to people” at his workplace often translate into doing their work for
them because he is afraid that if he gives them orders, he will lose them as acquaintances.
Although he recognizes the inadequacy and the danger of his strategy, he does not know what
else to do and feels frustrated because of that. Resolving this issue is particularly complicated for
Mike because he believes that helping others is “a positive thing”—despite others’ telling him
that it is not necessarily so. He also acknowledged that sometimes people do not appreciate his help:

> Sometimes they don’t want [help]. I will help people even though I keep going the extra distance for people. Some people say, “Let them help themselves.” “Why you get in . . .” I have a tendency to . . . It’s a positive thing. I wanna help people. And sometimes I go the extra distance I don’t have to go, or I go into other people’s territory I’m not supposed to go into.

Mike’s relationship with his wife is even more complex. The two met through a dating agency: “I couldn’t find anybody, and so . . . I knew, for me, it was the only way.” Although they have been married for 19 years, and have two children together, when asked about his marital status, he replied: “I’m married—in the word,” and then, “Married—sort of.” When I asked him to clarify what he meant by that, he replied that after their autistic son was born, 10 years ago, his marriage qualitatively changed:

> We had very good life together—we moved different places, we had kids. She got a good job. And then, we had our child with autism, and, sort of . . . that affected [taps the table several times with the pen] us—big time.

Currently, Mike said, his wife does not want to have an intimate relationship with him—or anybody else—and they are, more or less, living in a co-parenting, businesslike, relationship, rather than a true marital relationship: “We are married in the terms of raising our children.” He explained:

> Basically, my partner wants to be more . . . just friends, raising the children and . . . and [pause] not, [pause] not to be, hmm [pause], you know, not to be [a long pause] husband and wife—lovers, that type of thing. [taps two times]

Naturally, Mike has a difficult time accepting this change in the relationship, particularly because he does not quite understand “why”:

> That’s tough after so many years, you know what I mean. I am very patient—she tells me I am patient, but . . . I’m a very patient person but . . . It’s almost . . . sometimes I almost feel like, maybe, I’m one of the children too, but she says I’m like . . . She sees me . . . well, she sees me like a brother, but I, you know, I am her husband—she calls me her husband—to other people, “This is my husband.” But it’s very difficult—for most people anyways—it’s difficult to have that excluded out of the relationship—and you don’t understand why, you know what I mean.
Nevertheless, Mike said that his wife is

very affectionate to me, you know . . . certain times in a day . . . in the morning, when I
go to work and at night time, we hold hands, but beyond that . . . [pause] you know . . . I
kiss her cheek, she kisses me, you know, and I will . . . you know, she will embrace me,
but only certain times of the day, like I said, [lifts his hand from the table and drops it
back making a sound] when I go to work and at night time.

Mike still loves his wife and believes that she loves him, but that she is “going through a change
in life”:

I love her very much [softly]. I know she loves me—I know she does—I can feel it. Okay.
It’s my own way, but . . . we’ve been together a long time . . . it’s just she can’t . . .
[pause] I don’t know—maybe it’s a change . . . I think it’s a change in life, like a . . .
ladies change in life, [lifts his hand from the table and drops it back making a sound] and
she just doesn’t want to be with anybody.

Part of his wife’s “change” Mike attributed to the stress associated with raising their autistic son
(“She’s got a lot of stresses; we’re trying to raise an autistic child”), and another part to her
blaming him for having an autistic child (and another one with learning disability). All this, and
perhaps some other factors, which Mike said he does not understand, made his wife change her
sentiment toward him so much that she told him that he “can go out and meet other women.” He
said that she often tells him, “You’re such a great guy, such a great father, husband . . . you’re
great person’ constantly. And it’s, like, ‘I want you to be happy.’” But he said, “I don’t wanna
go; and we got everything going really well together; and we do really well together as a team.”
(Mike expressed this sentiment several times during the interview. For example, at another time
he said, “We get along really well; we communicate really well; we work as a team marvelously;
we enjoy each other’s company—I enjoy her.”)

Although Mike still hoped that his marriage will work out in the future, he recently tried to meet
other women. However, after the initial contact, things did not go well: “I have . . . not in a very
big way, but I have tried to meet other ladies in terms of friendship. I tried different methods, and
they’ve all failed.” He blamed misunderstanding on the part of these women for these failures.
He said,
I didn’t mean to do things or say things or . . . and it ended up coming back in my face. And I tried to establish a . . . a friendship, and it all . . . it ended up being . . . was . . . [pause] a misunderstanding, and I didn’t even do anything wrong.

According to Mike, these misunderstandings could be summarized as “somebody tells me to call them, and then they say they’ll call me back, [pan clicking] and they don’t.” Although he said he knows the rules (“I know that if somebody doesn’t want to talk to you, they don’t have to”), he once called a woman because “I thought the person had lost my telephone number or something,” and that became a huge problem. Now, he does not call even when he is given a phone number and told that he can call. Instead, he waits to be called but gets disappointed when women say they will call but never do. He does not understand why. However, when talking about his “inability to communicate effectively,” Mike mentioned his inability to understand non-verbal communication, which might play some role in these difficulties:

It’s hard to explain—you can . . . you can learn all these techniques to communicate but, if people . . . if people genuinely say to you, “You don’t GET [strongly emphasized] . . . You don’t get certain cues that I’ve given you” . . . [thought left unfinished]

Although Mike finds it difficult to deal with not being accepted anywhere, despite not doing anything wrong—that he is aware of—and in fact doing everything he can to make people like him, he believes that with some assistance “with understanding people more and relationships,” as well as himself, he will be more successful.

Mike’s awareness of his own contribution to his social isolation is very different from Pierre’s implicit confidence in his social understanding. Indeed, Pierre never mentioned any need for acquiring “more understanding of people,” relationships, or himself, and, when explicitly asked about it, he vaguely replied that “maybe” it could be helpful. Furthermore, whereas Pierre made his asocialness a matter of time (he said that it “takes [him] a little while to get friendly with people”), Mike is aware that there is something missing on his part but that he just does not know what. He finds this frustrating because he feels that he knows what the rules and strategies of relationships are and that he is a “gentlemen” (“I’m an officer and a gentleman,” he said), but this is just not enough.
9.3.1.1.3.1.3  Sarah

Unlike Pierre, but like Mike, Sarah did not define herself with reference to her social difficulties; instead, she defined herself in terms of her social strengths. Nevertheless, she identified her social difficulties as her major weaknesses, presenting an interesting blend of socialness and asocialness. For example, Sarah described herself as a “sweet [and] kind” person who never “really say anything mean to anybody.” On the other hand, she considered her difficulties with “understanding other people’s body language” both her greatest weakness and the aspect of self that she dislikes the most. She admitted that this difficulty often leads to misunderstandings at her work. She gave an example of not understanding when other people are angry.

It is interesting that Pierre, Orville, and Mike did not even mention the problem of understanding body language, although the problem is said to be characteristic of autism (APA, 1994). Of course, not mentioning the problem does not mean not having it. Unfortunately, from my role as an interviewer, I was not in a position to assess this—by the definition, I conveyed meanings verbally. However, as already discussed, Pierre did not seem to have such problem—at least not with regard to understanding conversational nonverbal clues such as pauses and voice hesitations.

In contrast to Pierre, who, from the third-person perspective, had a problem with eye contact but who dismissed its significance as “his” (or real) problem, Sarah identified establishing eye contact as her second, sociality related, weakness. She said, “I used to have problems looking people in the eye, but I am getting better at that.” Although she contributed this improvement to her increased conscious reminders “to keep telling [her]self to look people in the eye,” during the interview, Sarah seemed to have forgotten to remind herself to do it, leaving me with the impression that perhaps this task is much more difficult in new situations, such as the interview, and/or with people she does not know. It is interesting that Orville also mentioned eye contact—although in passing, in reference to what others have told him he should do “better”—but he, like Pierre, and unlike Sarah, did not think that he should bother with it. It is also interesting that Mike, whose eye contact was relatively good, did not mention ever having such problems.
Perhaps one of the reasons why Sarah did not define herself in terms of her asociality could be found in her high satisfaction with her current social life: she said that she is “happy” with it and rated it 5 out of 5. She said, “I realize that I am much more happier with my social life than before.” Although she admitted having difficulties making friends when she was younger and often feeling “very hurtful [and] rejected” when people “would decide not to be [her] friend anymore,” she currently has three “best friends,” whom she has known for several years and whom she sees several times a year but in the meantime chats with them on the phone or on the Internet. As she put it, “I actually have friends that I stay connected with.” She also said, “I always have fun with all three of them, spending time with them [. . .] watch[ing] movies at one of their place or go[ing] to a movie [. . .] celebrat[ing] birthdays. [. . .] One of my friends has a cottage up North, so I usually go up with her.” Consistent with her rating, Sarah did not express a wish to have more friends, nor more frequent contacts with the existing friends, nor did she express an explicit longing for romantic relationships the way Pierre, Mike, and Orville did. Even when pressed, while talking about her future, she said that “maybe” she will get married, but that was not something she was thinking about at the moment. It should also be noted that Sarah mentioned (several times) having a very loving family, which perhaps adds to her current satisfaction and the absence of the need for neither improvement of her existing social life nor inclusion of her social difficulties in her self-definition.

9.3.1.1.3.1.4 Jimmy

Like Mike, Jimmy also defined himself, at least in part, in terms of his socialness. He said, “I am a nice person, fairly perceptive, understanding.” When explaining why he considered himself a “nice person,” Jimmy, said, “I’ve always wanted to make people around me happy. I’ve always been concerned about how people around me feel.” He illustrated his claim as follows: “Even people that I don’t like or people that really rub me the wrong way, I would kind of go out of my way to still, you know, be nice.” He gave the following example:

I have a friend who’s pretty hard to be around. He’s kind of a jerk, most of the time. And I’m, more or less, the only friend he has left, and he is kind of . . . he can be kind of abusive towards me, and stuff like that, and I continue to be his friend because I know it’s not his fault—people are the way they are—and, you know, all of our other friends kind of abandoned him, and I stick with him. Yeah.
Jimmy said that he is a “perceptive person” because “I can, sort of, read people, fairly well—get an idea of how other people are feeling, or thinking, or what motivates them, and things like that.” When asked for an example, he replied, “If someone comes to me and is complaining about their girlfriend, something like that, telling me about an argument that they’ve had, I always, I will always kinda see things from both sides.”

Although Jimmy acknowledged similarities between being “understanding” and being a perceptive person, he suggested that in the former the emphasis is on trying: “I think, just trying to understand is important.” In fact, he considered his willingness to understand his main strength: “I TRY to understand, definitely.” He explained:

[I] try to be understanding of every situation and person that I am around. I don’t judge. I try not to judge or draw any conclusions without having all the information, kind of thing, which I think is kind of rare in people these days. [. . .] Anything . . . any person that I meet, I try not to judge them right away because your instinct is to do that, I think, you know, that’s just what we do, we have to characterize people, and I try not to. Anything that I see on TV or hear in the news, I won’t automatically, sort of, make any conclusions without knowing the whole story. [. . .] If there’s someone, like I said, who . . . you meet a lot of people in life who . . . people [you] don’t necessarily like, or who come across as a jerk, you know, like bosses, I always . . . I always, you know . . . I know that it’s not their fault—no one would ever intentionally wanna be that way. [. . .] I try to understand myself and other people and what makes us all tick and how, you know . . . how we relate to each other, and all that. [. . .] [I am] sympathetic.

Nevertheless, when asked about his weaknesses, he admitted, “My social skills. I don’t have any.” When probed, he corrected himself: “One on one, I can get by. More than one person, and I get in a trouble.” When asked to say more about these troubles, he replied, “Well, it’s just a lot of anxiety, and I either don’t talk, or say the wrong thing, or, you know, like, that kind of thing.” Like Sarah, Jimmy also found it particularly difficult to talk to customers at work: “Having to talk to customers was always a big problem and always, always, an issue.” However, whereas Sarah’s problem stemmed from her difficulty to read others’ body language, Jimmy’s problems came from the issue already identified by Pierre and Orville—small talk. He elaborated:

A lot of owners, or general managers, would expect you to just, sort of, make the rounds of the restaurant and make small talk with people and just chat with people and make people feel welcome—that type of thing—and I could never do that really effectively.
Unlike Pierre and Sarah, but like Orville and Mike, Jimmy identified his inability to form and maintain relationships as his main social difficulty. For example, asked what he likes least about himself, Jimmy said,

The social problems—the fact that I have a lot of problems relating to people. I mean, I’d like to have a lot of friends, but I just don’t know how to . . . it’s . . . it doesn’t work that way for me. I mean, that’s more of a, kind of, a general statement, I guess, that . . . [sighs] it’s hard to say specifically, but just when I’m around people, I just . . . I shut down, I don’t know how to . . . I don’t know how to behave, I don’t know how to . . . [pause] Just the anxiety . . . I feel anxiety about everything. I feel afraid of everything. I’m afraid to [sighs] just go walk into the store . . . going to the store causes me anxiety, leaving the house, sometimes. Any . . . any situation, anything new scares me—I hate that. [pen click]

Unlike Pierre, but like Sarah, Orville, and Mike, Jimmy also remembered that his social difficulties stretch as long as his earliest memories:

Ever since I was a child . . . you know, some of my earliest memories are, like . . . my first day of school, I just sat in the corner and screamed all day basically until it was over. [...] Like a parade went by my house, and I didn’t wanna anything to do with it—I would just hide. Or weddings—any kind of group things. My family, I never felt close to my family at all. Any family gatherings, I would always just sit in a corner and be quiet, things like that. And that kinda [inhales loudly] continued through my whole [slight pause] life. [slowly and in low voice]

In fact, Jimmy selected one of these group events—the earliest one he could remember—his uncle’s wedding, before he started going to school, as one of his self-defining memories. He described it as follows:

I just have some pictures really, just images, but I remember being . . . everyone gathering at my grandparent’s house, and all his family being around, just a crowd of people and all the excitement, I just freaked out. I just was in the corner kinda freaking out, screaming and crying, and wanted nothing to do with any of it; someone had to take me home.

Jimmy believed that the reasons why he “freaked out” were all of the people and the noise. I was just generally afraid of other people, anytime there were other people around me I just get anxious and there was a lot of them, a lot of
people I didn’t know, you know, my parents were probably busy running around and just
the whole kind of chaos situation.

Jimmy also remembered another group event, when he was about “five, six, seven”:

I do remember being at a party one time. It was a kid’s birthdays party, or something, and
just being afraid, and just, sort of, kind of, you know . . . All the mothers were off in one
room, and all the kids were off in another room, and I was just clinging to my mother and
just afraid—just afraid of the other kids, afraid of the other people, not wanting to be
there.

Jimmy’s later life experiences were not much different:

I can remember, kind of, like, junior high school and high school. I remember feeling,
hmm, kind of . . . [sighs] kind of conspicuous or, you know . . . I just . . . I always wanted
. . . always wanted to hide—always feeling like I was being [pause] watched or judged,
you know. I didn’t like . . . I just never liked being in groups, being with other people,
really—yeah, just feeling different.

When asked whether he wanted to be alone, or whether he wanted to be with others but was
afraid of them, Jimmy replied,

Hmm, both really. I mean, there’ve been times when . . . I’ve always felt kind of
compelled to be alone and to isolate myself. I do like to be alone. So certain times, I just
don wanna be around people. [sighs] But I think, maybe, as I’ve grown older, I do have
more desire to be around people, but I just don’t. I just feel very anxious about it, and I
don’t feel like I have the ability to do it. Like, I don’t know how to meet people.
Maintaining relationships, I’m not very good at.

In summary, as presented by Jimmy, his main social difficulties were both similar and dissimilar
to those of other participants. Forming and maintaining relationships were the major issues for
Orville and Mike whereas Pierre and Sarah acknowledged them to a much lesser extent.
Likewise, whereas Pierre and Orville acknowledged difficulties with small talk, Mike and Sarah
never mentioned any such difficulties. However, with the exception of Orville, who once
mentioned “almost” being afraid of approaching people, other participants never talked about
social fear or anxiety whereas Jimmy identified them as the main source of his social difficulties,
both in the past and currently, which raises the issue of the relationship of social anxiety and
autism. (Note that although Sarah’s psychiatric report did mention her social anxiety, Sarah did
not talk about it during the interview.)
Jimmy’s social strengths also both resembled and differed from those of others. Like Jimmy, both Sarah and Mike defined themselves with reference to being good and nice people. However, no other participants mentioned being understanding of other people. It is interesting that, if Jimmy’s claim, as well as his diagnosis of Asperger’s Disorder, are correct, with such ability, he would be very rare, if not unique, among autistic individuals. Most specifically, his ability to understand others, including their minds, would contradict theory of mind’s claim that the lack of such ability is a core “deficit” of autistic individuals. Indeed, “reading people” (“how other people are feeling, or thinking, or what motivates them”), which Jimmy said he does well, is exactly what autistic individuals are said not to be able to do (Baron-Cohen, 1995).

9.3.1.1.3.1.5 Alan

In contrast to all other participants whose self-descriptions I reviewed so far, who used at least one social attribute to describe themselves, Alan did not do so, at least not directly, and defined himself in terms of “split personality,” “many obsessions,” and “partial self-sustainability” instead. (By “split personality” Alan meant “one moment I seem like perfectly normal, perfectly in control, but the next moment I could flip out, kick things, make angry-looking face, shouting and screaming, and going crazy like Incredible Hulk, yes.” He explained this further as “It’s like your mind is there but you can’t stop what you’re doing, it’s like you’re a different person, it’s like that.”) However, his second self-characterization, many obsessions, contains as one of its main components a social obsession, talking to strangers, which I already introduced in the introductory sketch of Alan. As he put it, “I just have this obsession, as I mentioned, talking to people who I don’t know or who look pretty. Talking to pretty girls or women.” He is aware that this is an unusual thing to do, at least in the society in which he lives. He said, “I know at the same time that people would think I am weird. My mom thinks if I stop talking to women, or stop talking to them completely, there is more chance of me getting a girlfriend.”

However, Alan said that the main reason for his talking to women on the street was not to find a girlfriend: “I am just showing them that I am friendly.” Although several incidents involving this obsession (some of which resulted in police intervention) made him aware that women do not
necessary understand his talking to them as a sign of friendliness and that they may even think that he is “a big threat to them,” he still has a difficulty accepting it, as the incident from the coffee shop indicates.

In addition to Alan’s clearly social obsession with talking to women strangers, he said that his other obsessions—with details and particular topics—make it “not so easy” for him to make friends. Indeed, he said that the most difficult aspect of his social life is “just trying to communicate, like I am talking to you without going into too much detail,” and “not to talk about what people died and what caused them to die, what age they were, what year they died in, those things.”

Although Alan considered at least two people his friends, one of whom is also autistic—but more severely than he is—he said, “I should try to make more friends.” Nevertheless, the way he put it (i.e., “I should”) suggests that he may not need friends the way Sarah, Mike, Orville, or Jimmy do, but more like Pierre does—as something that would be good to have. Certainly, like Pierre, but unlike Mike and Orville, Alan never talked about his feelings of loneliness or isolation. Even when talking about the future, he only vaguely mentioned a girlfriend: “If I could try to find girlfriend.” Indeed, when thinking about his goals for the next 5 years, he almost forgot to mention a girlfriend. Thus, after he talked to some extent about his main goal of becoming self-sufficient, and after I asked about any other goals, he replied, “No. I think that’s about it. Oh, yes, also to get a girlfriend as well.”

In summary, in contrast to all other participants, Alan’s asocialness appears to be related to his obsessions, some of which are social, some not. It is also interesting that his social obsession (with talking to pretty girls) is both an indicator of his socialness, as it is clearly an expression of his need to socialize, and of his asocialness—because of his difficulty in estimating the appropriate time and place for the expression of his needs.

9.3.1.1.3.1.6  Howard
Like Alan, Howard also did not explicitly refer to the social domain among his three most important characteristics, choosing his interests in sport and traveling and his enjoyment in his job instead. However, when asked about the most enjoyable aspect of his job, he replied, “Friendliness, friends.” He also chose “work” as one of his most important life experiences. When asked to say more, he said, “Keeping everyone happy,” once again suggesting that the social aspect of his work was very important to him. Thus, it could be argued that, like Alan, at least indirectly, he also included his socialness in his self-definition. In addition, it is important to note that he did mention being loyal to family as his fifth important characteristics: “I like family. I enjoy family. I enjoy my [relatives, and] meeting my cousins.”

However, although Howard admitted having difficulties in “all aspects” of social life, unlike all other participants, he found it hard to identify what these difficulties were. Here is one of our exchanges on that subject:

L: Many autistic people find it difficult to deal with some aspects of social life. Do you?
H: [long pause] All aspects of social life. [L: All aspects.] I have problem with social [life].
L: Uh-huh. So what is the most challenging about social life for you?
H: [pause] I don’t know. [pause] Saying the wrong thing. [L: Saying the wrong thing.] Saying too much information [L: Uh-huh.]—that’s what my parents would tell me a lot of time.
[. . .]
L: Okay. So that’s one thing. What else—what other aspects of social life?
H: [long pause] I am not sure.

Several other attempts at soliciting more information about Howard’s social difficulties were equally unsuccessful. For example, when asked, “Do you ever have difficulty in communications with people?” he replied, “No.” Likewise, when asked about the most difficult aspects of life to deal with, he replied, “My handwriting.” When asked for one more feature, he responded, “Autism.” However, when asked What aspect of autism, his response was, “Reacting properly in public. Doing social skills in public.” He then vaguely mentioned a breakdown in public, but could not (or did not want to) remember any particular incident involving it. However, at one point he did seem to suggest that not having many friends was one of his social problems. Thus, when asked whether he remembered having any difficulties with social interactions, he said,
Yeah. I have very few friends. Most of my friends actually come from autism, or work, or baseball. I don’t have any friends, like, if I walked away from [the] program [inaudible], I would not be involved with people from [autism] program very often unless I [run into them] on the street, or something. I don’t stay involved. I have no friends from high school, or college, or anything. […] My actually . . . FAVORITE FRIENDS? Favorite friends are my parents.

Nevertheless, despite this acknowledgment, Howard later dismissed not having friends as a real problem by suggesting that the reason why he does not have many friends is because he is not interested in having them. When asked to describe his friendships, he replied, “I don’t have a lot of friends outside of my world—out[side] of my baseball [group], or whatever [taps]. I don’t have any friends from high school—anything like that, so. It’s nothing that I got interested in.” He also said, “I don’t look for people.” Asked how often he sees the person whom he considers a friend from one of his groups, Howard replied, “Couple times a year. [I should] send him an email but I keep forgetting, so.” He also said that he never wanted to have more friends because “I was happy the way it was.” Indeed, Howard reported being perfectly happy with his current social life, which he described as “Autism events, and baseball events, and that’s about it. And sporting events [pause]. And family functions.” On a scale from 1 to 5, he rated it as “A five. It couldn’t be better.” Further questions about whether he would like to have closer friends than the ones he currently has, or more friends, or a girlfriend, all received the same answer, a firm “No.”

In order to understand Howard’s satisfaction with his social life, it is important to remember that he said that he likes spending time with his family and his relatives and that he found “friendliness [and] friends” the most enjoyable aspect of his job. Moreover, it is also important to consider his answer to a question about positive aspects of autism, to which he laughingly replied, “You get attention when you are autistic. I get attention all the time. […] And everybody loves me.” (Indeed, as I mentioned in my introduction, Howard is a very likable person, and I have no doubts believing his estimation.) Perhaps this is why Howard never feels lonely and does not need a close friend or a girlfriend.

However, it is also important to note that during the interview, Howard made two remarks (i.e., “Nobody could live with me” and “Nobody would live with me”) that cast some doubt on his willingness or ability to admit his real social needs for the fear of rejection. In other words, Howard
may have accepted a story he told me about not needing close social relationships, including romantic ones, as his way of coping with negative expectations.

In summary, Howard expressed his socialness by acknowledging his enjoyment of being with his family and relatives, in participating in group meetings related to sports and autism, and in positive social contacts at work, to which he contributes by doing good work. On the other hand, despite acknowledging having problems with “all aspects of social life,” Howard explicitly identified only one of these problems, which he shared with Jimmy—“saying the wrong thing.” Thus, like Pierre, but unlike other participants, Howard did not explicitly acknowledge having difficulties with forming and maintaining social relationships (or rather, he recanted his once-made acknowledgment of such difficulties) and maintained that his lack of friendships was the result of his disinterest in them.

9.3.1.1.3.1.7 Geoff

Unlike any other participant, Geoff did not use any either implicit or explicit social attributes to define himself, referring to his intuition, love for music, and spirituality, instead. However, he still identified his social difficulties, which he called lack of “smart social instincts,” in the area of dating in particular, as his biggest weakness. He said that he is “clueless with dating.” For example, “[When] someone looks at you in a certain way, that’s supposed to mean something, and you’re supposed to respond, and I just don’t get it. I don’t get it.” He also said,

This has happened numerous times [long pause] where, you know, I would be with a woman, say, whom I met in some circumstance—whether it was at school or at work—and I wanted to say something, or wanted to express interest, and I was too scared to, and I didn’t. And this has happened to me hundreds of times.

Geoff’s difficulties with intimate relationships are also reflected in his decision to get married while still an undergraduate student “to the first woman [he] dated” despite knowing that they did not have much in common:

We really didn’t have anything in common. We liked different things, our personalities were different, you know. I was kind of shy, and a bit scholarly, she was very blunt and assertive. It was just not a good match.
Geoff also said,

This person and I were totally wrong for each other. And I still wasn’t quite self-aware, you know, that I could acknowledge it or admit it, but on some level I knew, and I did it anyway. And I should not have gone out with this person more than two or three times. Like if I met someone now who was like this person, and we had a date, there would be only one date. There would not be a second one. So there is no way I should’ve married this person, but I did.

Geoff attributed his hasty decision to the history of rejections: “I was making the decision to get married out of desperation because I assumed that this was the only person who would ever want to be with me, and so I’d better . . . you know.” He added,

It was weird, because in some ways . . . I mean, I hadn’t up to that point had a girlfriend, had anything at all, so in some ways, it was like, Finally, I got something. So that was good. That was a good thing about it. The bad thing was, you know, it was the wrong relationship with the wrong person, and so, you know, there were all sorts of problems, and fights, and not getting along, you know, and eventually unhappiness, and also, you know, I was very . . . well, I think we both tended to . . . we were both trying to work out our sexual stuff, and we were both very inexperienced, and it just didn’t work out, and we just gave up. So there was a sense, you know, for most of the marriage we were just roommates.

It is interesting that Geoff attributed his marriage problems to the interpersonal incompatibility—in personality, interests, sexual preferences, and cultural background—and never talked about any specific problems that might stem from his lack of social skills. Likewise, although Geoff was employed for many years, he did not mention any social difficulties he had on his jobs, nor did he mention any such difficulties in any other context.

It is also interesting that, like Howard, Geoff also claimed that he did not need friends. He considered three people his friends, one of whom he sees several times a year, and with the other two he exchanges infrequent emails, with gaps between them of several months to several years. Talking about his friends, he remarked, “I’m not the kind of person who needs a lot of friends, and I find too many friends a burden.” When asked how many friends he would like to have in future, he replied, “A few close friends would be good.” Asked to be more specific, he said, “Maybe three” but then corrected himself by saying that maybe even one close friend would be
enough: “It’s hard for me to know right now.” Nevertheless, he later said that even if he did not have any close friends that would not be devastating for him: “Having a couple of close friends or not, it’s not really important.” Indeed, when specifically asked about it, he admitted that he did not feel any specific need for a close friend nor did he really miss having a close friend. He also said,

Friends aren’t that important to me, like, if I lost all my friends tomorrow, that wouldn’t be that great, but I don’t feel I would be devastated or unable to go on. So it’s not really an issue, I don’t think.

Geoff’s current social life consists mostly of regular group meetings with members of two interest groups whose meetings he attends at least once a week and whose members he considers friends. He found his experience with one of these groups the most enjoyable aspect of his current social life and described it as follows:

At the [Eagles] group, we meet at the library, and then we go out afterward to a local pub, and we just sit around and socialize. And I’m use to it now, but the first couple of times I did it, it was so new to me—that I was sitting in a pub with my friends. This was really, really new. And it was wonderful. So I still feel, you know, it’s something I have never experienced up to that point really.

Geoff rated his social life 4 “because compared to all the other people I don’t have a real active social life, but I don’t really need one.” In fact, he said, “For me this is great, and it’s plenty, and I wouldn’t actually want, you know, ton of . . . more, and more, and more friends. I’d find it too overwhelming.” Nevertheless, despite reporting not needing more, or closer, friends, Geoff’s acknowledgment that being with a group of friends felt “wonderful” the first time it happened, despite not having the need for it prior to the experience, might mean that his denial of his need for friendship may be, at least in part, due to the fact that he “never experienced” true friendship before. Thus, had he had a real friendship and he lost it, perhaps he would have felt differently about it. Moreover, his acknowledgment that he would like to “[meet] somebody, whom I love very much and it’s really the first relationship I’ve ever had where everything is clicking” also suggest that his real need for human relationships might be deeper than he suggested.

9.3.1.1.3.2 Interpretive Summary
In this section, I review participants’ self-definitions with a special focus on definitions related to 
a/socialness.

9.3.1.1.3.2.1 Variety of Self-Definitions

So far I discussed Pierre’s and other participants’ self-definitions to the extent to which they 
were similar to Pierre’s. I now briefly summarize all self-definitions made by participants 
regardless of whether they were already reviewed or not. (The full list of self-definitions by 
participant appears in Table 5.)
Table 5 Summary of Participants’ Self-Portraits (Self-Descriptions and Self-Evaluations)

<table>
<thead>
<tr>
<th>Par.</th>
<th>Self-definition*</th>
<th>Strength</th>
<th>Weakness</th>
<th>Self-likes</th>
<th>Self-dislikes</th>
<th>Self-rating b</th>
</tr>
</thead>
<tbody>
<tr>
<td>P</td>
<td>Intellectual; dreamer/imaginative; anti-social [asocial]</td>
<td>Imaginative; logical</td>
<td>Indecisiveness; getting easily discouraged</td>
<td>Loyalty; imagination</td>
<td>Indecisiveness</td>
<td>3</td>
</tr>
<tr>
<td>M</td>
<td>Hard worker; try to be good to people; serious</td>
<td>Perseverance; researching; helping people</td>
<td>Really terrible at relationships [...] I want to basically love and be loved, but I just don’t</td>
<td>To go the extra mile to make something happen</td>
<td>Inability to understand myself [and others]</td>
<td>2.5</td>
</tr>
<tr>
<td>O</td>
<td>Loner; introvert; bad habit [...] my fingers and my nails all the time [...] always, on edge</td>
<td>Design sense; writing</td>
<td>Understanding [...] everyday chitchat (not knowing this language [that allows human bonding])</td>
<td>Ability or sense of being [...] feeling a common connection with nature</td>
<td>Lack of being able to communicate in the intimate sense with people</td>
<td>4</td>
</tr>
<tr>
<td>S</td>
<td>Organized; reliable; sweet/nice/kind</td>
<td>Punctual; reliable</td>
<td>Understanding other people’s body language; used to have problems looking people in the eye</td>
<td>Enjoy life</td>
<td>Understanding other people’s body language</td>
<td>4</td>
</tr>
<tr>
<td>A</td>
<td>Split personality [behaving differently under stress; losing self-control]; obsessed with things; partly self-sustainable</td>
<td>To work, work disciplined [...] try not to go to too many details; not to talk too much about things; trying to look decent;</td>
<td>Sometimes getting carried away [...] blowing up and, getting upset very easily; being too finicky; saying hi to so many people or just to some pretty girls who walk by, or try to get too close to some dogs too often</td>
<td>I don’t try to do these things [obsessions] in public</td>
<td>I look a little bit overweight or eat too much; having a [nega]tive outlook on life in general</td>
<td>2</td>
</tr>
<tr>
<td>G</td>
<td>Intuitive; love music/creative; very spiritual</td>
<td>Courage; I’m organized; I have a good eye for detail</td>
<td>Very self-critical; I take rejection very personally</td>
<td>Persistence</td>
<td>Negative expectations; body image</td>
<td>3</td>
</tr>
<tr>
<td>H</td>
<td>Sport fanatic; love to travel; enjoy my job (loyal to family, easy going; hard worker)</td>
<td>Memory</td>
<td>Handwriting; autism</td>
<td>Computer skills</td>
<td>Handwriting</td>
<td>4</td>
</tr>
<tr>
<td>J</td>
<td>Relatively intelligent; nice/perceptive/understanding; artistic (open)</td>
<td>Try to be understanding; artistic; pretty good with words and writing</td>
<td>Social skills</td>
<td>Try to understand things (people, situations, life); artistic side</td>
<td>The social problems [...] problems relating to people</td>
<td>2</td>
</tr>
</tbody>
</table>
Note. All descriptors are direct quotes; quotation marks are omitted to avoid cluttering the table; text in parentheses indicates clarifying information as said by the participants; text in square brackets indicates editorial remarks. Italics indicate original emphases. A = Alan; G = Geoff; H = Howard; J = Jimmy; M = Mike; O = Orville; P = Pierre; Par. = participant; S = Sarah.

aSelf-definitions in brackets are not used in data analysis.

bRefers to rating of self-liking.
Each participant produced at least 3 self-definitions—2 participants produced more than three: Howard (6) and Jimmy (4). Data analysis is performed based on the three self-definitions participants selected as being the most descriptive of them. (Self-definitions that were not included in data analysis do not significantly change the observed pattern of self-definitions.) The categories and the grouping criterion were selected to allow for comparison with the relevant autism literature: the categories used in data analysis were *personality, autism, interests, behavior,* and *other*; the grouping was based on the best-fit criterion. The categories were mutually exclusive. Consequently, self-definitions that could be grouped into more than one category were included in the category where they fit “most easily” from the perspective of the mainstream literature. For example, although Alan’s two self-definitions—“split personality” (i.e., lack of self-control) and “obsessed with things”—could fit into a broader conception of personality, they fit more easily into “behavior” (i.e., behavioral difficulties) and “autism” categories, and were thus not treated as personality characteristics. This is also true for other “autism-related” self-definitions—“anti-social” (i.e., asocial) and “loner”—which could be included as “personality” characteristics; however, I judged that they more easily fit into the “autism” category. As would be expected for the general population, most participants used at least one personality characteristic to define themselves (6 participants used at least one such characteristic, jointly producing 15 personality characteristics): intellectual and dreamer/imaginative (Pierre); hard worker, try to be good to people, and serious, (Mike); introvert (Orville); organized, reliable, and sweet/nice/kind (Sarah); intuitive, creative/love music, and spiritual (Geoff); intelligent, nice/perceptive/understanding, and artistic (Jimmy). (See Table 6 for a summary of this information.) It is also important to note that all 4 self-definitions that were not used in data analysis—that is, the attributes that were not among those the participants chose as their 3 most characteristic ones—fit into this “personality” category: easy going, loyal, and hard worker (Howard); and open (Jimmy). (For the list of all self-definitions see Table 5.)

Three participants defined themselves in terms of their autism-related characteristics: anti-social (i.e., asocial; Pierre), loner (Orville), and obsessed with things (Alan). Two participants used

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18 All self-descriptors in this paragraph are direct quotes. However, because using multiple quotation marks would make the section cluttered, they were omitted.
Table 6 Categories of Participants’ Self-Definitions

<table>
<thead>
<tr>
<th>Category</th>
<th>Self-definition</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality</td>
<td>Intellectual, dreamer/imaginative (P); hard worker, trying to be good to people, serious (M); introvert (O); organized, reliable, sweet/nice/kind (S); intuitive, spiritual, creative/music lover (G); perceptive/understanding, intelligent, artistic (J)</td>
<td>15</td>
</tr>
<tr>
<td>Autism</td>
<td>Anti-social [asocial] (P); loner (O); obsessed with things (A)</td>
<td>3</td>
</tr>
<tr>
<td>Interests</td>
<td>Sport fanatic, love to travel, enjoy my job (H)</td>
<td>3</td>
</tr>
<tr>
<td>Behavior</td>
<td>Bad habit [nail biting] (O); split personality [violent outbursts] (A)</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>Partly self-sustainable (A)</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>24</td>
</tr>
</tbody>
</table>

Note. A = Alan; G = Geoff; H = Howard; J = Jimmy; M = Mike; O = Orville; P = Pierre; S = Sarah.

their behavioral difficulties to define themselves: bad habit (i.e., nail-biting; Orville), and split personality (i.e., lack of self-control; Alan). One participant (Howard) defined himself entirely—if only the three most important self-definitions are considered—with reference to his interests and likes: sport fanatic, love to travel, and enjoy my job. However, it is important to note that, as already mentioned, all three of Howard’s “additional” self-definitions are personality descriptors: easy going, loyal, and hard worker. Finally, one participant’s (Alan) self-definition of “partly self-sustainable” (i.e. independent in some areas) could not easily fit into any of the existing categories and was treated as “other.”

Other possible relevant groupings are as follows: 5 participants defined themselves in terms of their social characteristics, using the following descriptors: anti-social (Pierre), try to be good to people (Mike), loner (Orville), sweet/nice/kind (Sarah), and perceptive/understanding (Jimmy); 4 participants referred to their ability-related characteristics: intellectual and dreamer/imaginative (Pierre), partly self-sustainable (Alan), creative (Geoff), relatively intelligent and artistic (Jimmy).

The presented pattern of self-definitions is at odds with reports that suggest that autistic adults usually define themselves in terms of what they do and what they like (Attwood, 2006; Hurlbutt
& Chalmers, 2004; Meyer, 2001). For example, Attwood wrote, “When I ask adults with Asperger’s syndrome to describe themselves, the descriptions are usually what they do, their job or special interest” (Attwood, 2006, p. 301). Moreover, he made a specific reference to the relative lack of autistic individuals’ references to their personality: “Adults with Asperger’s syndrome often describe themselves in terms of their interest rather than personality” (p. 188). One possible way to account for this discrepancy is by reference to the different context in which the self-descriptions were obtained. That is, it is possible that participants in a research study may have a broader mindset than clients in clinical (Attwood) or professional (Meyer) settings, which could explain why participants in this study made more references to their personalities than was previously reported.

It is also interesting that most participants (6) defined themselves solely (5) or predominately (1) in terms of their positive personal characteristics. In other words, only 3 participants (Pierre, Orville, and Alan) used negatively valenced attributes (5 attributes; 2 related to social difficulties: being asocial and a loner; and 2 related to behavioural difficulties: having a bad habit and obsessions and lacking self-control), and only 2 participants (Orville and Alan) used more negatively valenced than positively valenced attributes. This finding could be taken to mean that, as other autistic individuals have argued, and as already reviewed, autistic individuals see themselves primarily as human beings with positive personal traits, and not as individuals with impairments, as academic literature tends to portray them.

9.3.1.1.3.2.2 Self-Definitions Related to A/Socialness

Variety of a/socialness definitions. Two participants (Pierre and Orville) described themselves as asocial and a loner, respectively. However, a closer examination of their accounts clearly demonstrated the limitations of these terms in that they show that these terms, at least the way Pierre and Orville used them, do not mean voluntary isolation or even preference for isolation, as usually assumed. Despite describing himself as a loner, which he appropriately supported by an over-half-a-century-long history of being alone, Orville clearly demonstrated that he is not a loner at heart. To the contrary, his whole life has been marked by intense longing and search for others with whom he could share his passion for nature and philosophical discussions, as well as
his affection, and his lack of almost any success in that regard. Likewise, despite defining himself as asocial, for which he provided plenty of support, Pierre also appears to be a caring person within his family and interested in intellectual and romantic relationships outside of it. Moreover, he was himself aware of the limitations of the word “asocial” and modified it appropriately by adding a “maybe” to it. Following Pierre, I too opted to use a special word to indicate this blend of socialness and asocialness of autistic individuals—a/socialness.

Participants in this study provided a wide range of self-definitions that utilized both their strong and weak social features. Their social self-attributes ranged from “asocial” (Pierre) and “loner” (Orville), on the one end, to “try to be good to people” (Mike), “sweet [and] kind” (Sarah), and “nice, perceptive, [and] understanding” (Jimmy), on the other end of the a/socialness continuum. Two participants’ indirect inclusions of their a/socialness are worth special consideration. Although Alan’s way of including his socialness in his self-description—“[obsession with] talking to pretty girls”—is rather indirect, through being part of his larger self-identified feature to which he referred to as “[having] many obsessions,” it is equally, if not even more, important to our understanding of autistic individuals’ a/socialness. I say even more because it is so subtle that it could easily remain unrecognized as part of socialness. The same is true for Howard’s treatment of his work as a major source of meeting his social needs, which leaves Geoff as the only participant who did not use his social attributes to define himself.

Although it is no news that at least some autistic individuals can talk about being “asocial” and “loners,” several things that participants of this study said about themselves, including what they meant by asocial and loner, are either new or, at least, not acknowledged strongly enough in the literature on autism. First of all, it is new that autistic individuals define themselves in reference to social strengths, as Sarah, Mike, and Jimmy did. And it is important that they did so because, in the literature on autism, it is usually forgotten that autistic individuals are, perhaps with some exception, first and foremost good people. Moreover, Mike and Alan’s accounts are particularly important because they illustrate well how autistic individuals sometimes try too hard to show their good side to others—Mike by doing others’ jobs at his work and Alan by showing his friendliness to female strangers. Unfortunately, these two accounts also show how others usually get the wrong message from autistic individuals’ efforts, perhaps because their acts of kindness sometimes seem too good to be true that they become suspicious. Moreover, both Mike and Alan
also showed how difficult it is to find and develop appropriate coping strategies to deal with this paradoxical situation where their best efforts are misunderstood for acts of malice. This seems to be particularly difficult for Alan, whose troubles deserve to be considered in more detail as their relationship to a/socialness is more intricate than it seems at the first glance.

Alan defined himself as a person who has difficulty with controlling his temper (or, as he referred to it, having a “split personality”) and who has many obsession, two of which directly related to his behavioral outbursts: “talking to pretty girls” (in order to show his “friendliness”) and an obsession with the “dark side” of the world (which he showed many times throughout the interview by over-mentioning details about the “big bad world,” as several quotes from his interview, as well as the next one, clearly show). Alan described an incident when he was 27 years old, which involved his being on a woman’s way when trying to hold a door for her, and which resulted in him being arrested:

I was arrested for smashing this window at [Oxford] subway station [. . .] because I was upset with this one lady. One lady was quite angry cause her kids were driving her nuts. She felt like choking them, or just strangling them, or pushing them heads in the water until the bubbles stopped, or drowning them in the bathtub and slitting their wrists and committing suicide, like [in] one episode of Da Vinci’s Inquest, there, because their kids were driving her crazy, or she had a bad day at work [emphasis added].19 So I was trying to hold the door for her, but I was partially in the way, and I just moved aside and I said, “Oh, I’m sorry, I’m really sorry, I didn’t want to do this” and she said, “Good m-o-o-ve ash-o-o-o-o-le”, you know, because she was having a bad day [emphasis added].

To summarize this story’s main points: In an attempt to show his friendliness, Alan held the door for a woman, but he forgot to (completely) move out of her way; however, when he realized it, he promptly apologized—twice and emphatically. This was not received as intended by the woman, and she responded as if Alan did something bad. Alan, who already had difficulty understanding the “dark side” of the world, could not at that very moment figure out why the woman reacted to a good thing in a bad way, and he went out of control, demonstrating, at least to some people—including the police officers—his asocialness. He then spent the subsequent 4 years (with all likelihood of continuation) trying to make sense of the woman’s actions. He did come up with an explanation, or he accepted it by rote from somebody else (most likely, his

19 I added the emphases in this quote to highlight the main point I want to make.
parents), but he could not quite easily incorporate it into his worldview, as the highlighted text indicates: he devoted more than half of his account of what happened to finding excuses for the motives of the woman who misunderstood his behavior. Indeed, he repeated twice the two possible motives of the woman—“[her] kids were driving her crazy or she had a bad day at work.”

When we consider Alan’s motivation behind his act that got him in trouble (i.e., to show his friendliness), it is reasonable to assume that he expected friendliness in return. Given this expectation, it is quite understandable how the woman’s opposite reaction of what he expected was more than he could cope with. He could not possibly understand how anyone, without having some extraordinary reasons, could interpret his behavior as anything other than what he knew it was. This is why when considering Alan’s main self-defining characteristic, “split personality” (or an inability to control his behavior when “big bad world” seems overly threatening), we should not forget that it is, at least in part, an attempt to cope with the unexpected consequences of his best attempts to express his socialness.

Social motivations. Participant’s a/socialness was also reflected in a wide range of reported social motivations, which ranged from a relatively high level of sociability from the early years, on the one end of the sociality continuum (expressed by Sarah, Mike, and Orville, and represented by Mike’s statement “I did like to hang out with kids”), to a relative lack of such motivation even in adulthood, on the other end of the continuum (expressed by Howard and Geoff, and represented by Geoff’s statement “Friends aren’t that important to me”). Between these extremes are Pierre and Jimmy, who reported a relative increase of social motivation in adulthood (as Jimmy put it, “As I’ve grown older, I do have more desire to be around people”), as well as Alan, who did not explicitly acknowledge his social needs, but whose behavior (i.e., “obsession of talking to pretty girls”) could be interpreted as being motivated by such needs.

Participants also differed with respect to the explicitness with which they expressed their social needs. For example, whereas Mike, Orville, and Jimmy clearly expressed their needs to be with others, which was also obvious from their entire interviews in that their accounts are clear expressions of suffering from social isolation, other participants were less convincing. For example, Sarah, Pierre and Alan’s accounts leave a lot of space for doubt about how much their
expressed social aspirations are their real needs and how much attempts to meet others’
expectations or to introduce some variety in their lives. Likewise, although Geoff and Howard
forcefully denied needing friends, their accounts also contained at least some indicators of a deep
need for human relationships (e.g., need for a romantic relationship and enjoyment in group
socializing, in case of Geoff, and enjoyment of work because of friendliness, as well as
enjoyment in group socializing, in case of Howard).

The mixture of a/socialness expressed by the participants in this study is consistent with Wing
and Gould’s (1979) classification of autistic children’s interactions into aloof, passive, “active
but odd,” and appropriate. From this perspective, based on self-reported social interactions,
Mike, Orville, and Jimmy’s, and possibly Pierre’s, interactions seem to best fit into a category of
appropriate interactions (involving enjoyment of social contact for its own sake) whereas
Howard and Geoff’s, and potentially Sarah’s, social interactions (at least those outside family)
seem to best fit the passive category. The “active but odd” category, which Wing and Gould
defined as “undertaken mainly to indulge some repetitive, idiosyncratic preoccupation” (p. 15)
seems a best fit for Alan’s social interactions. The fact that nobody fits into the aloof group is
also consistent with Wing and Gould’s observation that this category is usually associated with
low-functioning individuals.

Varieties of asocialness. Consistent with literature on autism (APA, 1994, 2000; Asperger,
1944/1991; G. Dawson & Toth, 2006; Kanner, 1943), according to which difficulties with
processing social information are defining characteristic of autism/Asperger syndrome, all
participants expressed having such difficulties; however, there was a wide range of kinds and
degrees of these difficulties. Social difficulties endorsed by participants in this study included (a)
forming and maintaining social relationships in general, and dating and spousal relationships in
particular, (b) understanding non-verbal communication, (c) small talk, (d) saying the “wrong
thing,” (e) social anxiety, and (f) eye contact.

(a) Consistent with the literature (e.g., APA, 1994; Attwood, 2006; ), most participants (7 of 8),
expressed having at least some difficulty with establishing and maintaining social relationships.
However, whereas some participants (Orville, Mike, Jimmy, and Geoff) considered their
relationship problems to be very serious, and accordingly, devoted a lot of interview time to
describing them, other participants either treated such problems rather lightly (Pierre, Alan, and Sarah) and, consequently, did not spend a lot of time talking about them, or did not even acknowledge having them (Howard).

Four participants (Orville, Mike, Jimmy, and Alan) identified not having friends, or close friends in particular, as one of their major problems, which is consistent with literature on autism (APA, 1994; Attwood, 2006). Also consistent with both clinical (e.g., Attwood; Ritvo et al., 1994) and autobiographical literature on autism (e.g., Miedzianik, 1986; Newport, 2001; Robison, 2008; Shore, 2001), 4 participants (Pierre, Geoff, Mike, and Orville) identified dating as a specific problem. However, they described their dating problems differently, or at different stages of what Luke Jackson (2002) called “dating game.” Thus Pierre and Mike seem to be “stuck” at its earliest stage of “presenting” themselves to others whom they do not know already. In Pierre’s case, the main issue was composing a profile he wanted to post on dating websites whereas in Mike’s case, it was getting past the “I’ll-call-you stage.” On the other hand, Geoff presented his main problem as being at the stage where he already liked someone but did not know how to express his “interest.” Finally, Orville saw his problem as one of his inability to “bond” with the person he liked and who also liked him. Both Mike and Geoff also talked about not being able to understand others’ non-verbal communication.

Other autistic individuals expressed similar problems in their autobiographies. For example, Stephen Shore (2001) wrote, “I was often lonely and wanted to date but I could never figure out how to go about it” (p. 96). Like Geoff and Mike, he also could not read “the looks”: “When being with my parents at a restaurant or elsewhere, they would remark that a certain woman was ‘giving me the eye.’ But it was nothing I could detect” (p. 93). Like Geoff, John Robison (2008) could not express his feelings; he described his first “Aspergian dating”: “I was far too shy and insecure to ever tell her how I felt about her. So we just talked and read and fixed tape recorders and walked into town every day” (p. 68). Like Mike, Liane Holliday Willey (1999) also talked about difficulties with “bonding” (using a somewhat similar metaphor to Orville’s “bubble”):

The men I had been dating were nice men who shared some of my interests and hobbies, but with each of them there was always an unspoken and unseen something that stood between us—like the curtain that kept the truth of the Wizard from the people of Oz. (p. 78)
The 2 participants who were married, currently or in the past, Mike and Geoff, also mentioned *spousal difficulties* including sexual discords; however, none of them talked much about specific difficulties in interpersonal relatedness, such as verbal expression of affection and reading the other’s nonverbal clues, which are usually mentioned in autobiographical literature (e.g., Newport, 2001; Slater-Walker & Slater-Walker, 2002; Williams, 1994, 1996b; for a review of these difficulties, see Attwood, 2006). From what they spontaneously said, their accounts differ in at least one respect: whereas Mike repeatedly mentioned his constant efforts to make his wife happy but not succeeding in it, Geoff’s account conveys a more passive approach to his marriage as if he simply waited for it to somehow end after he realized the “incompatibility” with his wife.

(b) In addition to Geoff and Mike, who mentioned having *difficulties understanding non-verbal communication* associated with dating, Sarah, as well as Mike, also talked about having this problem in other contexts. For example, Sarah mentioned not being able to recognize when the customers at work are angry, whereas Mike talked about his inability to “get” social cues in general. Other autistic individuals also often talk about the issue, which is thought to be one of the core symptoms of autism (APA, 1994). For example, Dominique Dumortier (2004) wrote, “Sometimes someone looks at me and I can’t interpret that look” (p. 81). Although there were not many opportunities to observe this during the interview, at least 1 participant (Pierre) appeared to have a good understanding of at least one of the non-verbal cues, voice hesitations.

(c) Consistent with the literature on autism in adulthood, 3 participants (Pierre, Orville, and Jimmy) reported having a lot of difficulties with *small talk*. Indeed Pierre found it to be the most challenging aspect of social interactions. Likewise, Orville said that it feels “like a foreign language” to him, and not “part of [him], part of system,” with which Jimmy agreed when he said, “I don’t have that,” referring to small talk. Indeed, being disinterested and/or unskilled in making small talk has been suggested as a defining feature of an autistic adult (Baron-Cohen, 2003; Frith, 1991; Gillberg, 2002) and is often used as one of indicators of Asperger syndrome when a diagnosis of this condition is considered in adulthood (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001; Baron-Cohen, Wheelwright, Robinson, & Woodbury-Smith, 2005; Ritvo et al., 2008).
Like Pierre, Orville, and Jimmy, other autistic adults also described small talk as extremely confusing, complicated, and energy demanding, yet unnecessary part of conversation (e.g., Dumortier, 2004; Edmonds & Beardon, 2008; Gerland, 1997; Grandin, 1995c; Holliday Willey, 2001; Robison, 2008; Tammet, 2006). For example, like Pierre, who said that he finds it “hard to be casual” and to “loosen up,” Dominique Dumortier (2004) wrote, “I can’t chat, I just don’t understand informality” (p. 77). Also like Pierre, Gunilla Gerland (1997), finds the question “How are you?” difficult to answer. She wrote,

To be normally polite still requires a constant effort on my part. I never seem to be able to get those standard phrases to come out by themselves. I don’t know what it is that other people do that enables them to answer automatically “Thanks, the same to you” when someone wishes them a nice weekend. I have to think all the time and remember what I’m expected to say. Sometimes when I’m rather tired, I forget and give whoever has asked me a long and detailed answer to the question “How are you?” Then I forget to ask back how he or she is, because when I don’t think all the time about how I am supposed to behave, it’s quite logical for me never to ask about something I am not interested in knowing. It is also hard work distinguishing the questions “How are [italics in original] you?” and “How are you [italics in original]?”, and deciding how much of an answer I am to give. I think I often answer more honestly than the questioner has intended. [. . .] Deep down inside me, I sometimes get so tired—you have such complicated rules in your world! And all the time I have to think and think and think about them. (pp. 254–5)

However, most participants never mentioned small talk as an issue. Closer examination of their reported social interactions seems to suggest that one possible reason for this omission could be their relative lack of experience with small talk. For example, Sarah, Geoff, and Howard never talked about seeking new relationships and, therefore, never got to the point of experiencing the small-talk problem. Likewise, Mike and Alan, who were actively seeking new relationships, reported several misunderstandings in even earlier stages of social interaction than small talk (i.e., initiating conversation), which means that their social interactions with people they did not know already were often thwarted before the stage of small talk.

(d) Two participants (Howard and Jimmy) identified saying “the wrong thing” or talking too much, as one of their specific problems. Indeed, this was the only social problem that Howard acknowledged, whereas in Jimmy’s case, it was only a part of his main problem with establishing and maintaining relationships. It is also interesting that Howard’s selection of this particular issue as his main problem was based on his parents’ observation, whereas Jimmy
extracted it from the repeated comments of people to whom he said “the wrong thing.” Other autistic individuals also sometimes find it difficult to determine what to say, when, and to whom (e.g., Dumortier, 2004; Carpenter, 1992). For example, Anne Carpenter wrote, “It is very difficult for even a high functioning autistic adult to know exactly when to say something, when to ask for help, or when to remain quiet” (p. 291).

(e) Two participants (Geoff and Jimmy) specifically talked about social fears and anxiety. However, whereas these problems were Jimmy’s major problems, which he developed before even starting school, for Geoff, the problems were limited to dating and were developed in response to several dating rejections in adolescence. Like Jimmy and Geoff, other autistic individuals also often report fear and/or anxiety associated with social contacts. For example, Tony W. wrote, “[I] Feared People and Social Activity Greatly” (Volkmar & Cohen, 1985, p. 50, capitals in original; see also Bemporad, 1979; Dumortier, 2004). Indeed, empirical studies have confirmed that social fear and anxiety often accompany autism (e.g., Bashe & Kirby, 2001; Kuusikko et al., 2008).

(f) Contrary to the traditional view that avoidance of eye gaze is one of the typical symptoms of autism (APA, 1994),20 only Sarah identified it as an issue, although currently present to a lesser extent than when she was younger, whereas Orville mentioned it only in passing, and not specifically as his problem. Moreover, only Sarah and Pierre had a conspicuously absent eye contact during the interviews. However, as already discussed, Pierre consciously chose to ignore the issue as irrelevant. It is interesting that Sarah said that “she used to have” an eye-contact problem and talked about her significant improvement with it whereas, from a third-person perspective, I still considered that there was plenty of room for improving it. One way to explain this discrepancy is to assume that the interview situation was new to her and that she had to concentrate more on answering my questions that, most of the time, she forgot to remind herself to also look at me, at least from time to time. Some support for this interpretation is offered by Dominique Dumortier (2004), who wrote,

20 According to the DSM-IV criteria, social impairments in autistic disorder are, among other things, manifested by “marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze” (APA, 1994, p. 75).
Eye contact can be a problem for me. I can make eye contact, but mainly with people that I know well. With people I don’t know so well I can manage if there is someone else present that I feel safe and comfortable with. It’s harder if I am on my own with someone I know and it’s completely impossible with a stranger. I then come across as even more autistic. (p. 81)

9.3.1.2 On Pierre’s Other Self-Descriptions: Strengths and Self-Likes

9.3.1.2.1 On Pierre as a Logical Thinker

When asked about his strengths, Pierre said that he is a logical thinker and supported his claim with appropriate examples. In this regard, he is similar to many other autistic individuals who consider themselves good logical thinkers (e.g., Grandin, 1995c; Holliday Willey, 2001; Robison, 2008; Schneider, 1999). For example, like Pierre, many other autistic individuals like to define themselves with reference to their reasoning abilities. For example, John Robison said, “I am very logical guy” (p. 188) whereas Temple Grandin (1995c) considers herself “a totally logical and scientific person” (p. 189).

However, clinical and empirical literature on logical thinking in autism is mixed. On the one hand, clinical accounts have long suggested that autistic individuals have good or outstanding logical reasoning abilities (e.g., Asperger, 1944/1991; Attwood, 2006; Hippler & Klicpera, 2003; Wing, 1981). Similarly, several empirical studies confirmed that autistic individuals possess either superior logical reasoning ability (M. Dawson et al., 2007; Hayashi, Kato, Igarashi, & Kashima, 2008) or that their abilities are at least comparable to those of control subjects (Scott & Baron-Cohen, 1996). On the other hand, several studies found evidence that autistic individuals may have difficulties with logical thinking (Minshew & Goldstein, 1998; Minshew, Meyer, & Goldstein, 2002; M. Solomon, Ozonoff, Carter, & Caplan, 2008; Van der Gaag, Caplan, van Engeland, Loman, & Buitelaar, 2005). However, these contradictory findings, for the most part, could be due to different conceptions of what counts as logical thinking, which, in turn, could suggest that autistic individuals could be both logical and illogical depending on the circumstances, as Nita Jackson (2000) already pointed out in reference to her own inconsistent logic.
9.3.1.2.1 Other Participants

Only 1 participant (Geoff) explicitly referred to himself as being logical, although not so much in reference to his current self, but rather how he was in the past; he contrasted himself as being more logical in the past to himself being currently more creative. However, Mike’s reference to his ability to “take a problem and close the dots,” as well as already-mentioned Orville and Jimmy’s references to their intellectual abilities, could also be taken as indirect references to good logical reasoning abilities.

9.3.1.2.2 On Pierre as a Loyal Person

When talking about what he likes about himself the most, Pierre made a reference to his loyalty and provided appropriate justification. Indeed, loyalty is often found in clinical (e.g., Attwood, 1998, 2006; Gray & Attwood, 1999), biographical (e.g., Dewey & Everard, 1974; Fling, 2000), and autobiographical literature on autism (e.g., Holliday Willey, 1999, 2001; Lawson, 2008b; Romoser, 2000), in particular, in reference to autistic individuals’ being loyal friends and employees. For example, Holliday Willey (2001) put loyalty at the top of her list of ways to describe an autistic person.

However, very little is known about loyalty or any other personality trait associated with autism. Only two empirical studies (Ozonoff, Garcia, Clark, & Lainhart, 2005; Soderstrom, Rastam, & Gillberg, 2002) explored personality characteristics of autistic individuals specifically. Unfortunately, they used personality questionnaires that did not include loyalty. Yet, some support for the prominence of loyalty among personality traits of autistic individuals could be found in qualitative studies that often report that autistic individuals consistently consider themselves loyal (e.g., Hurlbutt & Chalmers, 2004; Molloy & Vasil, 2002).

9.3.1.2.2.1 Other Participants

Only 1 other participant (Howard) made an explicit reference to himself as being “loyal,” in his case, to his family. However, Jimmy’s remark about remaining friends with a person who,
according to him, did not deserve his friendship, is a clear, although implicit, recognition of loyalty—although Jimmy referred to it as being a “nice” person.

9.3.1.2.2.2 Other Participants’ Strengths and Likes

When considering their strengths or aspects of self they liked the most, like Pierre, other participants also often referred to their talents and abilities. For example, they mentioned having good researching (Mike), writing (Orville and Jimmy), artistic (Jimmy), and design abilities (Orville), “ability or sense of being . . . feeling a common connection with nature” (Orville), good memory (Howard), good attention for detail (Geoff), and good computer skills (Howard). They also singled out several personality characteristics such as perseverance/persistence (Mike and Geoff); willingness to “help people” and “to go the extra mile to make something happen” (Mike); courage and being organized (Geoff); “trying to be understanding” (Jimmy); and being punctual and reliable (Sarah). Finally, Alan identified several unique attributes, most of which related to self-control: “work discipline, […] try not to go to too many details or obsess about things,” “trying to look decent, not to talk too much about things,” and “try[ing not] to do these things [related to his obsessions] in public.”

It is interesting that whereas Geoff and Orville considered having good attention for detail a positive attribute, Alan selected “not go[ing] to too many details” as his strength, illustrating how a positive feature, if present in its extreme, could become a source of weakness, as well as how being able to control it could, in turn, become a source of strength, as Alan’s selection of several of his other positive attributes from the self-control category suggest. (It may be important to note that Orville did not mention this attribute when asked about his strengths but identified it as one of the positive aspects of his autism, as will be discussed later.)

9.3.1.3 On Pierre’s Other Self-Descriptions: Weaknesses and Self-Dislikes

9.3.1.3.1 On Pierre’s indecisiveness
Pierre said that his greatest weakness is his indecisiveness. There was plenty of evidence throughout the interview that points to the accuracy of this self-characterization with regard to at least one aspect of his life, his current employment status. For example, although the last—and only—time Pierre was employed was two years ago, he does not seriously look for a job. In fact, the last time he searched for jobs on the Internet was “couple of years ago.” (He did apply for one “library job” just a few weeks prior to the interview, which, from Pierre’s diaries, appeared to be the only application he had submitted since his last job ended and he did so only after somebody told him about the job.) In our first conversation on the topic of looking for work (in our first interview session), Pierre said that he is looking for a job “off and on” and that although he was not looking at the moment, he was “planning to get serious, shortly.” He also said that he found a “company in the Yellow Pages that has career counseling” and that he thought it “might be useful.” In our second interview session—one week after the first one—Pierre said that he feels ashamed of being unemployed and of still depending on his family. However, our subsequent exchange did not convey the same sentiment:

L: And so what have you done from the last time we’ve seen each other—from last Monday until today—in terms of making it different?
P: Not much. I’m going to update my CV and then contact that job centre I mentioned.
L: So that’s going to be in the near future, right?
P: I hope so.
L: Okay. But in the past, what have you done to improve that?
P: Well, as I said, I was at the [TFC] [agency that specializes in providing help with job search to individuals with disabilities] for a little while.
L: That was two years ago, you told me, right?
P: Yes.
L: And after that?
P: And after that I . . . I’ve been on my own.

A month later—in our last interview session—after Pierre mentioned that “getting a job” is one of his goals for the future, I asked him about the ways he could achieve this goal. He first mentioned finding a new job training organization (adding that his father had already found one that he thinks “has possibilities”) but then said that the first thing would be to update his CV. When I asked him when he plans to do that, he replied, “This week sometime.” When I met with Pierre a month later (regarding his diary) and asked him how his job search was going, he replied that he needed to update his CV. When we met almost five months later to review the interview
transcript and his diaries, he was still unemployed, and when I asked him if he contacted that job training organization, he said that he did not.

Pierre’s identification of indecisiveness as his greatest weakness is also consistent with his decision to seek help from a psychiatrist regarding it (as well as regarding the associated feeling of depression). However, when I asked Pierre whether he thinks he can change his indecisiveness, he was not quite sure that he needs or wants to change it. He said, “Maybe, like, I can be [emphasis added] decisive sometimes, like, when the circumstances are right.” This statement complements his initial response well: “I can be [emphasis added] indecisive” and shows that Pierre does not think that his indecisiveness is the problem all the time but only in some situations. One example of his decisiveness is seeking psychiatric help. (Perhaps “the circumstances [were] right” then.) Other examples of his decisiveness include making decisions regarding his education (such as switching from math to history, choosing a particular university, and choosing continuing education courses) and shopping when he lived away from his parents for one year (about which Pierre made a special note commenting that he enjoyed that year—which he also chose as his happiest life experience—because he liked making his own decisions “about what food to buy and such”). This last example also indicates that Pierre did not have a lot of opportunities to practice every-day decision making until he was 33 years old.

At the first glance, this mixture of decisiveness and indecisiveness may appear puzzling and leads one to ask, “Why can’t Pierre apply his dictum ‘If you don’t make decisions you are avoiding life’?” One way to start making sense of it is to consider the complexity of the decisions involved and the knowledge about one aspect of the world that is perhaps outside of Pierre’s knowledge—employment. Decision making in a vocational context is much more difficult than in the contexts Pierre mentioned (shopping and education). Although choosing a job appears similar to choosing a field of study in that it involves considering one’s abilities and interests, it is also very dissimilar to it in that job options are not as straightforward as fields of study are. For example, there is not just one job for a historian but many, some of which do not even have an obvious connection to the subject matter (such as a speech writer). Jobs are also not to be found at a particular place, nor are they there all the time, like fields of study are. So clearly, one needs some knowledge about these issues—which Pierre has recognized and has
already sought the help of a specialized employment agency—before one can even start looking for a job.

Pierre’s difficulties become clearer when we consider the fact that Pierre does not want to pursue a career in the field of his primary expertise—history (except perhaps as a researcher)—and is actually in an unusual position of having to look for a job in areas in which he does not have necessary qualifications: He said he was not interested in teaching but would like a job involving writing, research, and translation. Choosing translation in languages which he only fully understands with a dictionary as his first career choice suggests that Pierre’s current career perceptions may not be very realistic, or practical. Pierre also does not seem to see his PhD degree (or education in general) as a means to an end but an end in itself. From this perspective, and given the fact that the financial support that he receives from his parents meets his current needs, it becomes obvious that Pierre is not particularly motivated to really look for a job—thus his indecisiveness. Taking this line of thinking further, we can imagine that Pierre would have no difficulty accepting a job in historical research, translation, or political writing—if offered. Perhaps this is what Pierre had in mind when he said that he looked “a little” at job search sites on the Internet, and there was nothing there for him (that is, none of the jobs were what he had in mind).

This line of thinking about Pierre’s indecisiveness finds some support in the psychological literature on decision making. This literature clearly indicates that it is not unusual for people to be decisive in some situations or domains but indecisive in others (although there are also people who are indecisive across situations and domains; Germeijs & De Boeck, 2002). Indecisiveness limited to career decision making is an important area of research in career psychology where the differentiation is made between career indecision and personal or trait indecisiveness (indecisiveness for all types of decision making). Research in this area has shown that career indecision does not necessarily imply problems with decision making in other situations (Germeijs & De Boeck, 2002). Moreover, this research has also shown that indecisiveness is only one of the factors contributing to career indecision and that lack of self-understanding, lack of motivation, lack of information, and the presence of various conflicts—both internal and external—are also important factors that can contribute to career indecision (Gati, Krausz, & Osipow, 1996; Germeijs & De Boeck, 2002).
A number of categories and subcategories of difficulties involved in the career decision-making process identified by Gati and colleagues (1996) point to the complexity of the issues involved in the career decision-making process and are helpful in understanding Pierre’s situation. For example, a category they call lack of readiness includes issues such as general indecisiveness regarding all types of decision making as well as a lack of motivation to engage in the decision-making process regarding one’s career. As we have seen, Pierre’s career indecisiveness seems to stem from his lack of motivation rather than from general indecisiveness. Other factors identified by Gati and colleagues that can illuminate Pierre’s situation include (a) lack of information about the steps involved in the career decision-making process, (b) lack of self-understanding, (c) lack of knowledge about the various occupations, and (d) lack of knowledge about the ways of obtaining information required for decision making. We have seen that Pierre does not appear to have difficulties with self-understanding (he is well aware of his strengths and weaknesses). Rather his difficulty appears to be in his understanding of his strengths as they relate to various occupations. As he put it, “I know I have some skills, I’m just not sure about what use the world would put them to.” Pierre also said he would like to know “what people like me were needed for. [. . .] That is, what sort of skills of mine are in real need that I should be offering—to put them to use for.” What Pierre told us about career counseling indicates that he also seems to possess at least some knowledge regarding steps involved in the career decision-making process as well as knowledge about the ways of obtaining information required for decision making. If we assume he has no inner or external conflicts regarding his career (he did not mention any), this analysis leaves us with two difficulties: lack of motivation and lack of knowledge about the fit of his skills and abilities with various occupations.

It may also be important to note that although indecisiveness is one of the DSM-IV diagnostic criteria for major depression and obsessive-compulsive personality disorder (APA, 1994), there are no known associations between indecisiveness and autism. However, autism researchers might be inclined to attribute Pierre’s indecisiveness to an impaired executive function—a well-known “deficit” of autistic individuals (Hill, 2004; Hill & Bird, 2006; Ozonoff, 1995)—which, among other functions, also includes decision making (Fuster, 2003; Stuss, 1992). Yet, Pierre is not indecisive across situations/domains. The way he put it—“I can be” (vs. “I am”)—clearly shows that Pierre does not believe that he is indecisive in all situations, although he strongly
believes that he is indecisive when it comes to finding a job. On the other hand, he is very
decisive when it comes to things he likes and needs (learning, singing, reading etc.), and his
indecisiveness comes to the fore only when he needs to decide about things he is expected (by
society) to want (e.g., employment), but for which he does not have an intrinsic need.

Although Pierre has termed his difficulty with career decision-making *indecisiveness*, and
although the same term is used in psychological literature for the decision-making behavior he
described, on closer inspection, it appears that perhaps another term—*ambivalence, procrastination, or lack of commitment to decision making*—would better capture Pierre’s kind of indecisiveness. As we have seen, Pierre’s major difficulty is not in deciding among different options, it is the lack of motivation to even start considering his options—in one specific area of his life.

### 9.3.1.3.1 Other Participants

It is interesting that no other participant mentioned indecisiveness during the interviews.
Nevertheless, from a third-person perspective, from the overall content of the interviews, it
appears that the participants widely differed in this trait: whereas some appeared to be very
decisive (e.g., Sarah and Mike), others seemed to be relatively weak in this respect (e.g., Alan).
For example, Sarah appeared to be very decisive when she had enough information on which to
base important decisions. Thus, although she always wanted to become a singer, she changed her
mind about it at the end of high school when she learned more about that career path. Likewise,
Mike talked about making the decisions he needed to make using the relevant information for the
basis of his decisions, such as about joining the army, marrying and joining two hobby groups.
On the other hand, Alan was still relying on his parents to make important decisions for him. (A
fuller discussion on participants’ decision making will be presented later.)

### 9.3.1.3.2 On Pierre’s Tendency to Get Discouraged Easily

As his second weakness Pierre identified his tendency to get discouraged easily. He believes that
this tendency has much to do with the way he currently lives his life. His example (‘I asked a girl
out once, but she wasn’t interested, and it will be a while before I ask a girl again”) indicates the
depth of this tendency: only one negative experience is needed to deplete Pierre of his courage to try again. From the psychological literature, we know that there are large individual differences in how people respond to negative experiences: some people try harder (i.e. do not get discouraged easily), others give up (i.e., get discouraged easily; C. Peterson, 2000, Scheier & Carver, 1985). We call the former optimists and the latter pessimists. Although based on the above description, one could classify Pierre as a pessimist, Pierre considers himself an optimist, at least with regard to his future. Nevertheless, there are other clues that could be cited in support of the interpretation of Pierre as a pessimist. For example, his skepticism about anything he had not seen (i.e., identifying with Missourians) could be seen as part of pessimistic cognitive style. Given that pessimism has been linked to feelings of helplessness, passivity, and depression (C. Peterson)—all of which are found in Pierre’s account of his life—it is not unreasonable to suggest that Pierre might be more likely to give up rather than trying harder when faced with challenges. However, as is true for other individuals (e.g., Cantor, Norem, Niedenthal, Langston, & Brower, 1987), it is also possible that Pierre is an optimist in some and a pessimist in other situations.

Literature on the persistence of autistic individuals in the face of challenges is scant and inconclusive. Only one study (Barnhill & Myles, 2001) explored explanatory styles of autistic individuals. In this study, one-third of adolescents diagnosed with Asperger syndrome obtained scores consistent with a very pessimistic style. This finding is consistent with some clinical observations (e.g., Gillberg, 2002) that suggest that individuals diagnosed with Asperger syndrome “may be known as ‘pessimists’” (p. 51). However, there is also autobiographical (e.g., Barron & Barron, 1992; Gerland, 1997; Grandin & Scariano, 1986; Holliday Willey, 1999; D. Williams, 1992) and clinical evidence (Attwood, 1998) that suggests that autistic individuals could also be self-determined, tenacious, and persistent.

9.3.1.3.2.1 Other Participants

Like Pierre, 2 other participants (Geoff and Jimmy) also showed some tendency to get discouraged easily. For example, like Pierre, Geoff also had negative experiences with dating,
and he never got over them: “I had sort of several bad experiences in a row when I was twelve and thirteen.” As a consequence of these experiences, Geoff said, “taking rejection personally [. . .] has gotten the better of me because I am now so afraid that I don’t try at all anymore.” He added, “There is a real frustration, for sure. And I don’t know what’s causing it, but there is a sense that with dating, that it doesn’t matter what I do, I won’t succeed. And it doesn’t matter what I do.” Unfortunately, Geoff feels that this pessimistic attitude with regard to dating has also transferred to other areas of his life. Thus, when asked what he likes least about himself, he replied,

I was noticing this the other day, and I think it comes through in various areas of my life, that I still seem to have negative expectations. You know, when I go in to apply for a job, I just assume, Why am doing this, they don’t want me. You know, that’s the first thing that comes to my mind. So, you know, it’s like I always expect negative outcomes, and I wish I could change that.

Moreover, when asked about his weaknesses he said, “One of them for sure is that I tend to be very self-critical.” He provided the following example:

This is just actually from yesterday, I was applying for [long pause] a job, you know, and I felt kind of awkward, and I was reflecting on why I haven’t had success over the past six months, you know. I had people say, “Well, the economy is bad,” and so on and so forth, but I tend to assume it’s all my fault. I’m doing it all wrong. And it just be me. I’m defective. I always assume the worst about myself—if things don’t go right that it must be [me].

It is, however, interesting that Geoff’s tendency to have negative thoughts about himself does not seem to discourage him from making efforts to improve his life. In fact, when asked what he likes the most about himself, he replied, “My persistence.” He explained, “I’ve been struggling with all these things in various areas, but I keep at it, you know.” One context in which he showed this trait is schooling: “I kind of gave up in the middle of my Masters, but because I like to finish everything, I thought I would carry on, I would get the degree. I’ll, at least, do that,” which he did. Geoff also talked about his persistence in the context of job search:

I’m very discouraged [by job hunting] but I keep . . . and I’m doing things that . . . if I had my choice, I wouldn’t be doing some of the things that I’m doing. I wouldn’t be walking into some place and saying, Hi, I’m [Geoff], here’s my resume. I wouldn’t do that. If I didn’t have to, I wouldn’t. But I’m making myself do it. And every time I do it, I still don’t like it. I feel afraid, I feel uncomfortable, but I do it anyway.
Like Geoff, Mike also considered himself a persistent person. He described himself as a “hard worker,” by which he means being persistent and never giving up. He explained that early in his life he learned from his father’s example that “if things don’t always work out for you, you just gotta keep . . . try, try, try, try, again.” And this is what Mike did his whole life: “It’s my only thing I know. You gotta keep working hard in order to achieve.” During the interview, he mentioned many instances of his persistence during his schooling, at his work, and in his marriage. For example, while talking about how overwhelming his work is for him, he said, “But I persevere.” He also said that he wanted his children to learn from him “that if things are rough you gotta work harder,” not give up.

Likewise, Orville also presented himself as a persistent person. For example, he said that he started “to search for an answer” about his social problems in his 20s, first reading books and talking to others about his problems, and later looking for a professional help, until he finally got diagnosed with autism when he was 50. As he put it,

[I] search[ed] for an answer as to why I was having this problem with social bonding over the years and reading as much as I could about it, even after going to [Montréal], searching for answers there. Even though I couldn’t find answers the first couple years, [it] didn’t stop me. I kept discussing it even with friends and people that I met at the college and that, and finally . . . getting these hints of an answer, pursuing it up until finding the person that was willing to give me the diagnosis.

Several other components of Orville’s account support the view of Orville as a persistent person. For example, he educated himself to become an electrician and earned his living as a self-employed electrician for many years. Likewise, despite occasionally re-considering his hopes that he will ever be able to “bond” with other people, he still persevered in believing that that will happen:

And after a while, I almost begin to wonder, If this bubble [that does not allow him to bond with others] is going to be a permanent thing around me all my life, what’s a purpose of trying to break out of it? If I can’t break out of it, I can’t. I might, as well, just relax and accept it as part of me [chuckles]—it’s what it seems to be a lot of times, but other people keep saying, “Don’t give up. One of days the bubble will burst, and you will connect with other people, and you’ll be glad you persevered all that time” [. . .] And you get both pros and cons of whether to persevere and how long it takes to get rid of this bubble and finally find the bond with even one other person or whether to just give up.
Like Geoff, Mike, and Orville, Sarah also never gives up. She believes that “if you stick to something, you will be able to complete and not give up.” She talked about her pride at completing a college program, without “many help from my parents, like, for the academics. I handled all the subjects and the assignments that were in the subjects I took on my own.” If she were not successful the first time, she said, “[she] would probably retake it again, keep working at it”—and she would not give up.

In contrast to all these participants, Jimmy said that he rarely finishes anything he starts. He gave an example of not finishing college: “I have a hard time finishing things. I actually went back to the college three times—for three different courses, and ↓ didn’t finish any of them [speaking softly].”

Although Howard and Alan did not specifically address the issue of persistency, what they did say seems to be more consistent with seeing themselves (as well as being) persistent than with getting discouraged easily. For example, Howard mentioned that he is a hard worker, which is supported by his life story, whereas Alan talked about his continuing efforts to learn the skills necessary for independent living despite having a “[nega]tive outlook on life in general.”

In conclusion, the participants in this study provided evidence of both persistence and a tendency to get discouraged easily, with persistence predominating for the group as a whole, which is consistent with autobiographical literature on autism (e.g., Barron & Barron, 1992; Gerland, 1997; Grandin & Scariano, 1986; Holliday Willey, 1999; D. Williams, 1992). As Gunilla Gerland (1997) suggested—and consistent with Orville’s life-long “search for answers”—persistence may depend on context; in some contexts, it is the only “choice”: “My ability just to go on and never give up was [. . .] partly due to the fact that these situations were always about things I thought vital [. . .] Quite simply, I couldn’t afford to lose” (p. 13).

9.3.1.3.2.2 Other Participants’ Weaknesses and Self-Dislikes

Note. All emphases in this section are original.
Unlike Pierre, whose two major weaknesses and self-dislikes (i.e., indecisiveness and getting easily discouraged) were not related to autism, most other participants identified their social difficulties as their most negative attributes: being “really terrible at relationships” and unable “to understand myself [and others]” (Mike); “[not] understanding [. . .] everyday chitchat [. . .], not knowing this language [that allows human bonding]” and “lack of being able to communicate in the intimate sense with people” (Orville); “[lack of] social skills” and “the social problems [. . .], problems relating to people” (Jimmy); “[not] understanding other people’s body language” and “problems looking people in the eye” (Sarah); and “autism” (Howard). Alan also mentioned behavioral difficulties that are sometimes associated with autism: “sometimes getting carried away [. . .], blowing up, and getting upset very easily”; “being too finicky”; “saying hi to so many people or just to some pretty girls who walk by, or try to get too close to some dogs too often.” In addition to Pierre, only 3 other participants identified their weaknesses and self-dislikes from areas unrelated—or at least not directly—to autism. In addition to already-mentioned self-attributes potentially related to getting discouraged easily (Geoff’s being “very self-critical,” “tak[ing] rejection very personally,” and having “negative expectations”; and Alan’s having a “[nega]tive outlook on life in general”), there were only two other weaknesses and dislikes in this category: 2 were related to body image: having a “[negative] body image” (Geoff) and “look[ing] a little bit overweight or eat[ing] too much” (Alan); and 1 to fine motor skills: having poor handwriting (Howard).

### 9.3.1.4 On Pierre as an Autistic Person

Pierre never used the words autistic or Aspergers to refer to himself in the interview nor in his diaries. However, in one of his 2003 diary entries, he commented on his description of himself on an online dating site as having the _geek syndrome_ (a popular label for intellectual but socially awkward people used in popular media; Silberman, 2001). In fact, Pierre is very selective with regard to which aspects of his diagnosis he accepts and which he does not: he readily identifies with connotations that go with _geek syndrome_ but not with anything that might suggest pathology (disability or disorder). Without denying having social difficulties, Pierre does not accept that being labeled autistic means being disabled, at least not in his case. Instead, he
appreciates the good aspects of autism (e.g., being logical, analytical, and non-conventional) and claims that he likes being different and that he would not want to be “conventional” (that is, non-autistic).

Pierre is not alone in such a positive attitude toward the diagnosis of Asperger syndrome. In fact, as reviewed in the introduction, there are many autistic individuals who, like Pierre, feel that they are different, not disabled (e.g., Holliday Willey, 1999, 2001; L. Jackson, 2002; Sinclair, 1992; D. Williams, 1996; see also Harmon, 2004; Molloy & Vasil, 2002; J. Singer, 1999; A. Solomon, 2008). However, Pierre’s attitude toward his diagnosis seems to be a genuine one and does not appear to be influenced by the neurodiversity movement. Thus, when I asked him in the follow-up interview whether he knew what “neurodiversity” was (which is currently an unavoidable term used in Internet discussions among autistic individuals and their supporters), he answered jokingly, “No, something about diverse nerves?” (January 15, 2009). Therefore, his feeling of genuine liking of his condition and not wanting to be different, in a way, contribute to the validity of the neurodiversity movements’ declaration that no “cure” is required for, at least, high-functioning autistic individuals (Shapiro, 2006).

Pierre said that his non-acceptance of the “autistic” label (despite being self-aware of his differentness from others) comes from his belief that his autism is “just one part of [him] that may or may not explain a whole lot.” Echoing Allport (1965), who also thought that “label does not explain” (p. 210), Pierre is also in agreement with Peter Jansen (2005), another autistic individual, who feels that any label reduces him as a human being:

A label, psychiatric or otherwise, is a convenient short-hand symbol for defining you as a person. I personally dislike it because it reduces the human being in all his complexity and layers of ego structure down to a single thought or concept, expressible in a single sentence or a short paragraph. It’s a handy short-cut for knowing those whom you have never met. I don’t want to have AS [Asperger syndrome] define me as a human being, partly because I don’t think any finite cluster of words and ideas ever could. A diagnosis is an idea, a static, inert framing of words, whereas a human being defies quantification. The human being is dynamic, able to change, grow, and evolve. (pp. 313–14)

21 Importantly, the term is also adopted by people who were never diagnosed with any of the autism spectrum disorders but who identify with some of their features. It is also used by individuals with various other conditions such as attention deficit disorder and depression (Harmon, 2004).
It should, however, be noted that this view is not shared by all autistic individuals as some see a great value in using the term autistic to “explain” themselves to themselves and others (e.g., Dumortier, 2004; Meyer, 2001). For example, Roger Meyer likes to describe himself as an autistic person even though he does not believe autism defines him:

I am an autistic person. Autism does not define me, but it goes a long way to “explain” me to myself and to others. It explains the similarity of my conduct with that of others in the same boat. We all handle our oars differently, even if we pull in the same direction. Autism does not explain the uniqueness of my being. My experience does that. Your experience explains your uniqueness. (p. 91)

Although Pierre did not say it, I believe that another reason why he might have preferred the word different as opposed to autistic could be that, as Wendy Lawson (2008a) said, “When one hears words like difference and diversity [italics in original], one feels a sense of colour and excitement. When one hears words like disorder and deviant, one feels fear and suspicion” (p. 63). However, despite Pierre’s non-acceptance of the diagnosis as a descriptive term for him, he did not deny that it brought him some benefits by allowing him to access services of a specialized employment agency. Again, this acknowledgment echoes that of many other autistic adults (for a review, see Attwood, 2006).

9.3.1.4.1 Other Participants

Orville. For Orville, being autistic meant feeling like living in another world—in a world of his own—which he likened to being “in a bubble.” He termed this feeling an autistic feeling and described it as follows:

I agree with those people [who] use that phrase “in a world of one’s own”—I feel a lot of times I am in a world of my own. No matter how much I try to connect with others, it’s a feel like I’m in a bubble, almost, and I’m trying to reach out, but almost, like this bubble around me is preventing me from connecting to others—it’s what it feels like. […] And [sighs], I guess, I am stuck in this bubble until the day I die. [That] feeling that sometimes comes over me is what I would describe as autistic feeling. Whether I am home alone, it feels like that, or whether I am at a group meeting, it feels the same way as well.
Despite this feeling of being in a bubble, Orville, like Pierre, did not believe that being autistic meant being wrong—just different. Thus, when asked about potential benefits of learning social skills, he replied,

I look upon it as a broader issue of not [starts lightly tapping the table] the person with autism being wrong and the normal person being right but more of interaction [increased tapping]—not of them training me but of training the normal person [increased tapping] as much as myself into compromising [stops tapping] and knowing each other better—that’s the way I look at [it].

Asked about his own compromising, and whether he felt that there were some areas of social life about which he would want to learn more, he answered,

I don’t think just learn—that’s what I’ve been trying to do all my life . . . is learn and . . . learn it in the cultural sense of the word—that’s the thing I keep trying to tell people . . . is that I feel personally I have a different culture than a lot of people, but I don’t feel it’s something . . . as though it’s something medically wrong . . . as though it needs to be fixed—that’s the way I look at it—any more than you look upon culture from another part of the world and tell them because they are not pro-Western they must be fixed. [laughs]

In fact, as already mentioned, Orville felt that learning and applying non-autistic people’s rules would mean pretending to be somebody who he is not and that he was not prepared to do it. As he put that, “So I have to be the person I am, and I’d like to find somebody else who is willing to accept me the way I am without me pretending to be normal some way [laughs].” To illustrate his view, Orville gave the following example:

She [his partner] said, “Oh, most normal males would behave this way.” And I kept trying to tell her, “But I can’t be compared to normal males—I can only be compared to myself,” is what I kept trying to tell her. But she keeps, and others keep, saying this idea that they can’t take me . . . and there’s all these others who would do it that way, “Why can’t you do it the way they do it?” type of . . . again, minority versus majority type of thinking. And I say, “Please don’t compare me, just treat me for what I am.” [laughs]

Orville believed that autism has many positive sides, including paying attention to details and three-dimensional thinking. Here is what he had to say about the former:

The details you can get down to [. . .] the small things that a lot of people can’t even notice, that . . . and also carries on into the design, like I said, in engineering and mathematical details. Even people . . . sometimes I tell them things in numbers, and they
look at me, or poetry, “How on earth do you remember that?” So all those details, I say, are some of the good things that go with being autistic, such as years ago when I read a book about the Greek golden ratio being most pleasing to the human eye and how mathematically it’s such an intricate number there with so many variables—I’m surprised how things work out—but even that number there I always remember as being one, decimal, 6180339887498948482 [slightly tapping while reciting the number] is that many decimal places. [laughs] Yet those numbers just don’t seem to ever go away from me [and] seem to be ready at any time just at the back of my mind. [chuckles]

With regard to three-dimensional thinking, Orville said,

A lot of people can think in two dimensions—they can see a plan of a floor—but it’s almost like I not only see the plan of the floor, but I see the walls, even if it’s not on the plan, and I see the layout and even begin to see how the pipes come down through, even if they run this way, this way, and this way, in the walls to get down. And other things even, like, landscape architecture—not only the plan of where the trees are about to be planted, but what it’s gonna look like after the trees are fully grown, and that, that are hard to explain to other people—is another [thing].

Orville had more to say about these features in response to the question of how he would be different if he were not autistic, to which he replied,

I’d say it’d be less detailed and more social. More depth of perception—not understanding, but perception—and all the variables that could go through all the . . . I don’t know what to call it, totality of possibilities out there, and that, that would be almost gone, and everything would be almost like just on the surface. I’d just see the table here, but it wouldn’t even cross my mind that there is wood in this table and things like that, that every time, now being autistic, when I see a house, I tell people that I don’t just see the house, it’s almost like all the details of the house come at me at once, whereas normal people, when they drive down the street, [they] see the front of the house—that’s the only thing that seems to come to them . . . is the front of the house as though . . . even if I remind them, “Well, inside the house, I’m sure there’s a living room, a kitchen, a basement, probably, a bathroom, quite sure, in the kitchen probably [a] sink,” and all the other details, it doesn’t seem to cross their mind at all. Just the front of the house is there and that’s it. I can’t relate to that then if I was normal, [laughs] but all these other details come to me. Like, when I’m driving down [King] Street [street where interview was], almost every house I see, all these details come to me. [chuckles]

Given these, and other, benefits of autism, Orville, like Pierre, believed that being non-autistic would be worse than being autistic. For him, it would mean being “almost half alive”:

From my present perspective, if I was not autistic, I would say, it would be worse because I wouldn’t . . . on a scale of 10, I’d say about 60 to 70 percent worse because
lack of depth, bonding with nature, and all, three-dimensional thinking would be all gone—is the way I look at it. It’s almost like, if I was not autistic, all these assets would be pulled away from me, and that. And, sure, these other assets, like being able to chitchat with people about, “Oh, did you hear about what happened with the soccer game the other night up at Toronto,” and stuff like that going on might be there, it still . . . I wonder if I would be alive or not—whether I’d be almost half alive at that time. [laughs]

In concluding his view on what it means to be an autistic person, Orville said,

People have said quite a bit, “Would you want to go for the therapy or treatment if you could get rid of your autism?” Well, better than the idea of getting rid of it, I’ve asked, “Isn’t there any way I can go and somehow learn the social means of bonding with other people without losing these others assets?” [chuckles]

**Geoff.** Like Pierre and Orville, Geoff also would not like the idea of losing his positive autistic features, although he would prefer not to have the social difficulties he associates with autism. For him, being autistic meant being “brilliant but challenged.” In other words, “there are some positive aspects and some challenges”:

I’d say one of the positive aspects is that [long pause] if I’m interested in something I can have a tremendous amount of focus and drive and I can just block everything else out and just zone in on it and pursue it—whatever end I’m looking to pursue. So I think for me that’s a great strength.

Geoff believed that if he were not autistic, “[the life] would be better in some areas, and worse in others.” It would be better because he would have those “smart social instincts. And that’s something I wish I could have. So in that sense if I could have that, it would be better.” Nevertheless, he would not like to trade the smart social instincts for his other autistic features:

But a lot of the things, you know, that, sort of, make me, me and give me that sort of focus and, you know, a little bit of quirkiness, and, you know, if that were to disappear, I wouldn’t like that very much.

**Mike.** For Mike, like for Pierre, being autistic meant thinking differently from others: “My thinking process is the opposite, sometimes. So I see, maybe, other things that other people don’t see about people and things.” Like Geoff, Mike also associated autism with an enhanced focus of attention: “If I can key into something, I can concentrate on it.” In an interesting twist, Mike also transformed his lack of social relationships into a “positive thing”: helping others and being
helped. He reasoned, “I wanna help people [because] I’m constantly looking for friendship,” and “[when] you wanna make friends [. . .] you end up helping people. And sometimes it could pay back. It could help because when you’ve help somebody, they might help you.”

Yet, despite all these positive aspects of autism, Mike would prefer not to be autistic. When asked what it means for him to be autistic, he replied, “It bites. It’s terrible. It’s not fun. It’s not good. It’s not a good place to be. I don’t wish it upon anybody.” He elaborated:

It hurts. It hurts. It [long pause] . . . doesn’t make me feel good. [. . .] No, it’s not a good place to be. You think overall, you look at a life, people accept you in many cases, especially in a professional realm, and you learn to be courteous, you learn all these rules, I’ve learned a lot of rules—how to be, but I don’t necessarily . . . I don’t fit in—and I never have. I don’t even fit in my job even though I’m accepted, but I’m also, from the way I term it, I’m on the social periphery. And because we have rules and comradeship, you are accepted to a degree, but you’re still not inside the social circle, even in your club. So I’ve learned to live with that, and it doesn’t bring me down. I just wander around myself. And I’ll meet work buddies and stuff like that, but beyond that, I never . . . “Hey men, let’s go out and go fishing,” you know what I mean? It doesn’t happen. So what’s it like, it’s not a good place, but you learn.

What Mike meant by “you learn” is that he accepted his autism and that he tries his very best to improve his life, every day: he learns new rules, explores new strategies, and, most of all, hopes for the day he will be accepted the way he is.

Jimmy. Like Mike, Jimmy would prefer not to be autistic despite feeling that there are some positive things about being autistic, such as being always honest: “Not understanding sort of social standards, not having that social filter, I don’t think that’s a bad thing. I’d rather be honest. I wish everyone were honest all the time.” However, for him, being autistic first and foremost meant having a variety of problems—social, emotional, and attentional. Here is his list:

I don’t feel bonds with other people, I have trouble just processing social situation[s], I never know how to . . . never feel like I know what to say or . . . I feel like out of touch with my emotions, I feel like I don’t know how to express my emotion, I never laugh. [. . .] It’s like my brain’s always going in different directions—all at once, all the time.

If he were not autistic, he said, “I think I would be probably more successful, professionally, financially, I would have a more active social life, I would, you know, be closer to my family
[and] other people.” However, he said, he got more “comfortable with [being autistic]. I don’t think of it as much of a . . . as much of a curse, I guess.”

**Sarah.** Sarah did not share any of these views. In fact, to her, being autistic did not mean much—at least not when explicitly asked about it. For example, although Sarah said that to her being autistic meant that “[she is] special,” she claimed, “I guess, I feel like I am normal as everybody else, which I am. Like, I try to live a normal life as everybody else.” Indeed for her, “life would have been the same with or without [autism].” And although Sarah identified two positive aspects of being autistic, “Having a normal life as everybody, that would be to me good about being autistic, and achieving your goals,” it seems that her understanding of “being autistic” was not the same as those of others. More specifically, whereas others in response to the question about possible good aspects of autism identified specific aspects of being autistic, Sarah identified aspects of an autistic person’s life *despite* autism, which is consistent with her belief that being non-autistic would be the same as being autistic.

However, one of Sarah’s remarks near the end of the interview casts some doubt in Sarah’s complete openness when she provided the above-quoted views. Thus, when asked if she could choose to live another life, what that life would look like, she replied, “I think if I am living another life, I would be living it without maybe my disability,” which perhaps indicates that being autistic is not quite the same as being non-autistic, as she previously suggested. Yet, Sarah’s above-quoted statements could also be interpreted as indicating that she accepted her autism and that she does not think much about it.

**Howard.** For Howard, being autistic simply meant “to have a label.” And having a label felt “good” to him—partly because he believed that everybody is autistic. Here is what he had to say in response to the question how it feels to be autistic:

> That’s . . . nothing . . . it is the way I am. I don’t know anything different. MY HONEST OPINION? It’s . . . everybody is autistic. Everybody has something wrong with them that would make them autistic—that’s my honest opinion. [pause] But I could be wrong.

Nevertheless, Howard’s answer also implies that for him being autistic also meant “ha[ving] something wrong with [you].” Asked about his life if he were not autistic, he replied, “I’d be normal.
But I wouldn’t know what that would mean because everything is normal to me.” However, as already mentioned, being autistic for Howard also meant getting more (positive) attention from others than he believed he would get otherwise: “You get attention when [chuckles] you are autistic. [. . .] I get attention all the time.”

**Alan.** For Alan, being autistic “sometimes [. . .] just feels awkward, that’s all, yes, feels unusual.” He identified several reasons for this feeling, including not knowing where he belongs:

> It just feels like it’s hard to just make a living, it’s hard to fit in. [. . .] It just feels . . . it feels like I am not quite sure [where] I belong, that’s what it is. Like, I don’t know where or how I belong, where I belong, what kind of jobs, or other things—education—I belong in, there.

When asked about life without autism, Alan said, “I don’t know. I don’t know. It’s hard to say.” (Because I felt that Alan was not comfortable talking about things that could not be changed, I did not ask further questions.)

### 9.3.1.4.2 Interpretive Summary

The participants differed in their subjective feelings about autism referring to a variety of notions already associated with autism: unconventionality (Pierre), thinking differently (Mike), living in a bubble (Orville), brilliance and challenge (Geoff), awkwardness and unusualness (Alan), specialness (Sarah), having a label (Howard), and “trouble just processing social situation[s]” (Jimmy). (See Table 7 for a summary of this information.) It is interesting that only Orville made a reference to living in his own world (i.e., bubble), which is, as already reviewed, a common metaphor in both autobiographical (e.g., Dumortier, 2004; Gerland, 1997; Grandin, 1995c; O’Neill, 1999; Prince-Hughes, 2004; Sainsbury, 2000; Sinclair, 1992, 1993, 2005; D. Williams, 1992, 1994, 1998) and biographical literature (Sacks, 1995) on autism. However, it is important to note that in another context, Geoff expressed the same sentiment when he said that he “feel[s] a bit like an alien in this world.”
Table 7 Summary of Participants’ Feelings about What It Means to Be Autistic

<table>
<thead>
<tr>
<th>Category</th>
<th>Answer</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phenomenology of being autistic</td>
<td>Being unconventional (P); think[ing] differently (M); liv[ing] in a bubble (O); [being] special (S); feel[ing] awkward [...] and unusual (A); being brilliant and challenged (G); hav[ing] a label (H); hav[ing] trouble just processing social situation[s] (J)</td>
<td>8</td>
</tr>
<tr>
<td>Positive aspects of being autistic</td>
<td>Good attention: attention to detail (O); focus and drive (G); concentration (M); different thinking style: logical, analytical, and out-of-the-box thinking (P); three-dimensional thinking (O); help[ing] people (M); getting positive attention (H); being honest (J); having a normal life [...] and achieving your goals (S)</td>
<td>7</td>
</tr>
<tr>
<td>Being autistic vs. being non-autistic</td>
<td>Being autistic is more positive (P, O, G); Being autistic is more negative: explicitly (M, A, J); implicitly (S, H)</td>
<td>3</td>
</tr>
</tbody>
</table>

Note. A = Alan; G = Geoff; H = Howard; J = Jimmy; M = Mike; O = Orville; P = Pierre; S = Sarah.

All but one participant in this study (Alan) identified some positive aspects of being autistic. (For a summary, see Table 7.) It is interesting that in the case of two such features, the views of at least some participants coincided. Thus, Orville, Mike, and Geoff agreed about the benefits of a good attentional focus. However, Jimmy’s mention of a lack of focus casts a doubt on the generalizability of the strong attentional abilities of autistic individuals, which has already been questioned in the literature on autism (for a review see, Allen & Courchesne, 2001). Pierre and Orville mentioned different thinking style (i.e., thinking outside the box and three-dimensional thinking, respectively) as an important asset of being autistic, which is also consistent with the literature (Asperger, 1944/1991; for a review, see Attwood, 2006). It is also interesting that other positive aspects of being autistic identified by the participants were derived from autism’s “negative” sides. For example, Jimmy said that “not understanding social standards [and] not
having [...] social filter” (because of autism) leads to honesty, which he highly values, as do many other autistic individuals (as already reviewed; e.g., Gerland, 1997; Holliday Willey, 1999; Williams, 1998). Likewise, Mike discovered that not having friends (because of autism) led him to always be good and try to help others in his attempts to establish friendships or maintain acquaintances. Finally, Howard believed that because he is autistic he is getting more (positive) attention than he would if he were not.

However, despite finding some positive sides of autism, the participants differed with regard to whether the positive aspects outweigh the negative ones. Thus, whereas Pierre, Orville, and Geoff expressed their views that being autistic is more of a good than bad thing, this view was not shared by the rest of the participants, who either explicitly (Mike, Jimmy, and Alan) or implicitly (Sarah and Howard) expressed their views about undesirability of autism. Pierre, Orville, and Geoff’s views are consistent with the previously-reviewed so-called neurodiversity view of autism as a difference rather than a disability or illness that needs to be cured (e.g., Sinclair, 1992, 1993; Holliday Willey, 1999; Lawson, 2000).

The participants also expressed their views at different levels of complexity and conviction. Thus, whereas Orville presented a very elaborate and convincing view on autism, most other participants (e.g., Pierre, Sarah, Howard, and Jimmy) did not venture outside their own experiences. And although in their attempts to understand themselves, Mike, Alan, and Geoff drew from others’ experiences, they did not make any obvious efforts at integrating these experiences into a general view about autism as Orville did.

### 9.3.1.5 On Pierre’s Self-Evaluation

In this thesis, I use the terms *self-evaluation, self-esteem, self-liking,* and *self-satisfaction* interchangeably to refer to how people feel about themselves. Such treatment is guided by William James’ (1890) original view of self-satisfaction as “a certain average tone of self-feeling which each one of us carries about with him, and which is independent of the objective reasons we may have for satisfaction or discontent” (p. 306). Although *self-esteem* is usually understood as meaning how people feel about themselves “on average” (for a review, see Leary &
Baumeister, 2000), in developmental literature, this global view about oneself is referred to as *global self-esteem* and is distinguished from domain-specific self-esteem (such as academic, athletic, and interpersonal self-esteem; Harter, 1985; 1999; 2006), whereas in personality literature, it is called *trait self-esteem*, which is defined as “a person’s long-term, typical, affectively laden self-evaluation” (Leary & Baumeister, , 2000, p. 3) and is distinguished from *state self-esteem*, which refers to a “person’s affectively laden self-evaluation in a particular situation” (p. 3).

Pierre said that he neither liked nor disliked himself and rated his self-liking as 3 out of 5. He said that he liked being logical, loyal, and imaginative but that he was not happy with being unemployed and not getting “much work done” and about “sometimes feel[ing] emotionally cold” and “some people find[ing him] remote.” Therefore, it appears that, at least when consciously considering himself as a person, Pierre takes his many strengths into account and balances them against his weaker sides. However, given that self-esteem can change on a daily basis depending on one’s events and experiences (Kernis, 2005), it is also possible that on another day, Pierre’s answer would have been different.

Although, as already reviewed, there are no empirical studies that investigated the self-esteem of autistic adults, three studies with autistic children and adolescents (Bauminger et al., 2004; Capps et al., 1995; Williamson et al., 2008) found that, like Pierre, in the interpersonal domain, autistic participants had lower self-esteem than control subjects; however, this did not have an influence on their global self-esteem. Consistent with these findings are also some autobiographical accounts which documented autistic individuals’ positive (e.g., Grandin, 1995c; Holliday Willey, 1999; L. Jackson, 2002) or neutral views of themselves despite their awareness of their interpersonal difficulties. However, it is also important to note that some clinical reports (Tantam, 2000b), case studies (DesLauriers, 1978) and autobiographical accounts (e.g., Andrews, 2006; N. Jackson, 2002; C. Mitchell, 2005; O’Neill, 2000; Spicer, 1998a) suggest that, as a consequence of not fitting in, persistent bullying, rejection from the opposite sex, and employment-related disappointment, autistic adults might be prone to low self-esteem. Literature on bullying also suggests that adults who, like Pierre, experienced chronic bullying as children tend to have low self-esteem (Olweus, 1993; Rigby, 1997). Given this evidence, as well as Pierre’s reported depressed moods and his tendency to get discouraged easily—which
psychological literature associates with low self-esteem (Harter, 1999, 2006; Orth, Robins, & Roberts, 2008)—Pierre’s self-esteem appears to be better than would be expected, which could perhaps be attributed to his high valuations of his intellectual and artistic abilities.

### 9.3.1.5.1 Other Participants

Like Pierre, Geoff also rated his self-liking as 3 out of 5. (See Table 5 for a review of the participants’ self-ratings.) When evaluating himself, he said he considered both his strengths and weaknesses: his courage, being organized, and having “a good eye for detail” on the one side, and being “very self-critical” and taking rejection “very personally” on the other. Mike, who rated himself similarly—2.5—also considered his strengths and weaknesses: his perseverance, researching, and helping people on the one side, and being “really terrible at relationships” on the other.

Three participants (Orville, Sarah, and Howard) were the most satisfied with themselves and rated their self-satisfaction 4. Orville explained his rating this way: “I like myself when I do things on my own, go to the woods, and explore and enjoy. The only part I don’t like is my financial situation.” Sarah justified her rating by “working [her] 2 part-time jobs,” whereas Howard said, “I like everything [about myself]. I take myself for who I am.” When asked why he did not say 5, he said “Five would be perfect. I could have said five [chuckles], but that would’ve look like I’m gloating, like I’m self-centered.” Had he had better handwriting, “[he]’d be perfect,” he said. On the other hand, Jimmy and Alan did not seem to particularly like themselves and rated their self-satisfaction 2. When explaining his rating, Jimmy said,

> I know that it’s not a logical thing for me to not like myself—things I don’t like about myself are not necessarily [pause] important—it doesn’t necessarily make sense, so I am trying to, sort of, see the other side and [pause] . . . and just try to, you know, like myself more.

Jimmy also said that his rating was based on his consideration of his strengths and weaknesses, as well as his regrets. He considered his “try[ing] to be understanding,” having good artistic abilities, and being “pretty good with words and writing” his strengths, and a lack of social skills his major weakness. However, he said, “What I think that I don’t like myself, I think a lot about
regrets that I have and things that I have said and done in the past that I wish I hadn’t have said or done.” He also said that he would have liked himself more if he had not had “all the fears and anxieties and insecurities” and if he were “more confident [and] little more successful.”

Evaluating his liking of himself, Alan said that he mostly considered his dissatisfaction with his weight and with his difficulty to get ready for living independently, and his satisfaction with his accomplishments (e.g., “when I do a very good job in gym”).

In summary, with the exception of Jimmy and Alan, the participants in this study more liked than they disliked themselves, perhaps suggesting that they value their strengths more than their weaknesses, which they all said they considered when making their evaluations. It is also interesting that none of the participants reported extreme liking or disliking of themselves (although Howard was rather close to the perfect liking) and that their self-liking clustered around the middle (range 2–4). This finding is consistent with some of the autobiographical accounts in which authors expressed both their high self-liking (e.g., Grandin, 1995c; Holliday Willey, 1999; L. Jackson, 2002; Schneider, 1999) and disliking (e.g., Dumortier, 2004; Edmonds & Beardon, 2008; N. Jackson, 2002; Spicer, 1998), perhaps suggesting that self-liking of autistic individuals might have a more normal distribution than usually assumed.

### 9.3.1.6 Summary

In contrast to scientific literature on autistic individuals, most of the participants in this study defined themselves in terms of their personality characteristics as opposed to their impairments (APA, 1994, 2000) or their interest and activities (e.g., Attwood, 2006; Hurlbutt & Chalmers, 2004). In fact, only 3 participants used any autism-related characterizations to define themselves: asocial (Pierre), a loner (Orville), and obsessed with things (Alan). However, whereas two of these participants (Orville and Alan) also referred to two potentially autism-related self-definitions (i.e., introvert and partly self-sustainable, respectively), the third one (Pierre) used two other attributes which were not related to autism (i.e., intellectual and dreamer). Thus, it could be concluded that 6 participants chose to define themselves using some terms that are not related to autism; of these, 5 participants defined themselves using exclusively self-attributes that are unrelated to autism such as hard working, serious, organized, reliable, sweet/nice/kind,
intuitive, spiritual, creative/a music lover, and intelligent. Around two thirds of the participants’
self-attributes were personality related: 15 out of 24 when only those self-attributes that each
participant selected as the three most characteristic ones are considered, and 19 out of 28, when
all self-characterizations are considered.

In addition, when considering their strengths or aspects of themselves that they liked the most,
the participants also referred to their personality characteristics and their abilities and talents. For
example, Pierre referred to his imaginative and logical abilities and to his loyalty whereas other
participants identified their perseverance/persistence, courage, and willingness to help and be
understanding of others; being organized, punctual, and reliable; having good researching,
writing, artistic, and design abilities, good memory, and attention to detail, as well as having an
ability to connect with nature and control one’s obsessions.

On the other hand, whereas when considering their weaknesses and self-dislikes, most
participants identified their social difficulties with forming and maintaining relationships,
understanding self and others, or their behavioral difficulties—most of which directly associated
with autism (in fact, half of the participants identified only their social, autism-related,
weaknesses and dislikes)—Pierre, as well as 1 other participant (Geoff), referred only to the
personality and cognitive characteristics not directly related to autism, such as indecisiveness and
getting easily discouraged (Pierre), being self-critical, taking rejection personally, and having
negative expectations and negative body image (Geoff). One other participant (Alan) also
identified having a negative body image as well as negative cognitive style, and only 1
participant (Howard) identified as his weakness a negative self-attribute that did not belong to
any of these categories: difficulties with fine motor skills (i.e., having poor handwriting).

Finally, most of the participants (5) liked themselves more so than they disliked themselves, with
1 participant choosing a neutral rating. Participants’ self-esteem ratings ranged between 2 and 4,
and they seemed to have more balanced views of themselves than is suggested by the existing
academic literature. Several participants seemed to particularly like their attention skills (3) and
unique thinking styles (2), which they believe are directly associated with their autism.
9.3.2 On Pierre’s Current Life

9.3.2.1 On Pierre’s Living Arrangements and (Un)Employment

As already mentioned, Pierre lives with his parents and is unemployed despite obtaining the highest level of formal education. He expressed his dissatisfaction with both his living arrangements and his employment status, and said that he is ashamed of being unemployed. Moreover, both finding a job and moving out were among Pierre’s most important goals for the next five years; in fact, finding a job was his most important goal. However, Pierre’s actions (or rather his inaction), as well as his not even mentioning these issues in his diaries may be interpreted as his being more content with his current situation than he is aware of—going by all the other things he said in the interview, he seemed perfectly fine with living with his parents (and his sister) and with his participation in several regular, as well as occasional, volunteer activities (e.g., singing, political campaigns, and community projects). In other words, it may be that what he has and what he does actually meet his current needs and that his expression of his dissatisfaction is a result of his consideration of what he knows should be expected of him. It is interesting that although Pierre said that he “feel[s] ashamed” of being unemployed and of depending on his family—and rated his satisfaction with his current employment status as 2 on a scale of 1 to 5—by the time of the interview, and for at least one year after, he did not even explore job opportunities seriously. Moreover, he was quite vague about the areas of possible employment.

Living arrangements. Like Pierre, three other participants (Sarah, Alan, and Jimmy) also live with their parents. (For a summary see Table 8.) However, in contrast to Sarah and Alan, who always lived with their parents, Jimmy lived on his own for the past 18 years. He moved out in his early twenties, after he finished high school, and until recently, lived separately from his parents—with a girlfriend or roommates. On the other hand, 4 participants (Mike, Orville, Geoff, and Howard) live on their own and have done so from their early adulthood. Not only do they live independently, but Mike and Orville also own houses and Howard owns a condominium.

Employment. Only 2 participants (Mike and Howard) were employed full time at the time of the interview, and although Sarah had two part-time jobs, they were not sufficient to support
Table 8 Summary of Participants’ Life Outcomes

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<th>Category</th>
<th>Subcategory</th>
<th>Beginning of study</th>
<th>End of study</th>
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<td>Life satisfaction</td>
<td>Satisfied</td>
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</table>

Note. aItalics indicate change in status from the beginning of the study (i.e., time when the interviews were conducted).
bApproximately 1½ years after initial interviews).

independent living. However, as already mentioned, Sarah’s employment status changed soon after the interview, and she was employed full time when last contacted, more than a year after the interview. Similarly, Geoff, who was previously employed for 14 years, was unemployed for about 5 years at the time he was interviewed but was just about to start working again, and if I had interviewed him only one day later, he would have been employed. As already mentioned, he had three part-time jobs when last contacted, more than a year after the interview.

The employment statuses of other unemployed participants did not change for the duration of the study: Jimmy, who was previously employed for about 20 years, was unemployed for about a year and was going to school at the time of the interview; at the end of study he was still unemployed but with a diploma in web design. Alan, who once held a salaried position for less than a year, was volunteering both at the beginning and the end of study, and Orville, who was employed for 25 years, was retired at both times.
It is interesting that both Geoff and Jimmy expressed their strong dissatisfaction with their previous jobs. In fact, Geoff, who started working after high school and was employed throughout his undergraduate and graduate studies, as well as for most of the time after, terminated his last employment because he wanted to try to do something more creative than was offered by the jobs he has had for most of his life—these were merely jobs he “could do,” not jobs he liked or had qualifications for as a sociologist. Some of his jobs included: a shipping/receiving clerk in bookstore, a stacker at the university library, an academic secretary at the university (6 years), note-taking, and closed captioning. After he left his last job, he spent several years writing his autobiography and was just starting to write a new book at the time of the interview.

I was supporting myself doing various office jobs, this and that [. . .] note taking and close captioning and stuff, but again it was something I could do, but it wasn’t really fulfilling. And then this book idea came along so now I’m trying to reinvent myself as a writer. But do you see what I mean?

Although Geoff hopes that one day he will be able to earn his living by writing, he recently realized that his financial situation at the time did not allow him to wait any longer for that to happen and that he needed to start working again without thinking much about job satisfaction. As a result, he once again had to accept yet another job he “could do,” this time as a courier, which he was about to start the day after the interview.

Like Geoff, Jimmy also expressed his unhappiness at his job, and when he got fired from his last job (which was not the first time it had happened), he did not want to start looking for the same kind of job. He decided to go back to school so that he can attain qualifications that would allow him to move from jobs he is “able to do” to jobs that he is both able and would like to do. He said,

I got into [the restaurant business] just out of . . . because it was easy, because I started off cooking, and I just kinda . . . just stayed in it. Hmm, and it’s something I’ve always been able to do, so I take jobs in it because they are available to me but I always hated it, so I’ve finally . . . I just kinda couldn’t do it anymore, and I’ve decided to go and try and take a course, and try to get into something completely different.
Like Jimmy and Geoff, Orville, who is currently retired, said that he would prefer to work if he could use his “sense of design” in his work. Moreover, both Howard and Mike, who are currently working full time, would like to have different jobs than the ones they currently have. Although Howard is currently happy with his job because it meets several of his needs—financial, need for routine, as well as some of his social needs—he said that in the future, he would like to have a job in accounting, in which he has a college degree. Likewise, although Mike is satisfied with his current army administrative job because it pays well, this is not the job he chose to do; rather, it was given to him because he could do it. Therefore, it is not surprising that he is already planning a new career after his impending retirement.

Participants also revealed several autism-related work difficulties. For example, as already mentioned, Sarah and Jimmy, whose work included interactions with customers, revealed their difficulties with understanding customers’ body language and with small talk, respectively. Likewise, Mike talked about his problem with telling others what to do—because of his fears of losing them as acquaintances—and ending up doing their work instead. Finally, Alan mentioned his difficulties with controlling his obsessions at his volunteer placement. For example, he described how his boss is not happy when he needs to take out his chewing gum at a particular time and how he “told me to stop doing it, ‘Throw out the gum right now,’ or he’ll start yelling at me.”

9.3.2.1.1 Interpretive Summary

The living arrangements and employment statuses of the participants in this study are consistent with the current literature on autism. Like most other high-functioning autistic individuals (Barnard et al., 2001; Engstrom et al., 2003; Howlin, 2004), half of the participants in this study live with their parents, and do not hold employment that can support independent living. For example, as already reviewed, according to a large national survey conducted by Barnard and colleagues in the UK, only 12% of high-functioning adults were employed full time while a quarter (24%) had no work-related responsibilities or were “helping out around the house” (p. 7). Although the ratio of employment in this study is higher (4 out of 8 at the end of the study), it is
reasonable to assume that this is due to the small size and selectivity of this study’s sample and that it is not representative of the whole population.

None of the 4 participants working at the end of the study (Mike, Sarah, Geoff, and Howard) held employments in their field of study. This was also true for 2 participants who held jobs of longer durations, or different jobs (Jimmy or Geoff, respectively), in the past. Consequently, they all expressed their job dissatisfaction—either explicitly or implicitly (by expressing their wishes for having jobs better suited to their skills and abilities). This situation is also highly typical of other high-functioning autistic adults (Attwood, 2006; Hurlbutt & Chalmers, 2004). Moreover, like participants in this study, many other autistic individuals hold any jobs that they “could do.” For example, Jerry Newport (2001), who holds a BA in Mathematics and who worked as a taxi driver for many years, wrote, “I have held many jobs. I do what is available. Sometimes that’s public speaking. Other times, it’s substitute teaching, pet-sitting or even delivering pizzas” (p. x).

It is also important to note that 2 participants whose jobs required direct communication with customers (Sarah and Jimmy), commented on their job difficulties stemming from a mismatch between their social skills (or lack thereof) and their job requirements. This type of work situation is also common among high-functioning autistic adults. Indeed, Mark Romoser (2000) coined a special word for it, “malemployment,” which he defined as “working not only far below your skill level but also at a task for which you are totally unsuited” (p. 246).

9.3.2.2 On Pierre’s Day-to-Day Life

As already reviewed, Pierre spends most of his time (around 8 hours a day) in solitary activities such as reading, writing, watching movies, and solving puzzles. He also has several household responsibilities such as gardening and shopping with his father, cooking, and bread-making.

Although Pierre’s daily reading and other intellectual activities may, at first glance, seem excessive, and as such may qualify as one of the three core symptoms of autism, “restricted repetitive and stereotyped patterns of behavior, interests, and activities” (DSM-IV; APA, 1994, p. 71), classifying Pierre’s interests and activities as such based on his presentation alone is not
straightforward. Restricted repetitive and stereotyped behavior, interests, and activities—labeled variously as rituals, obsessions, stereotypical behavior, insistence of sameness, unusual and/or excessive preoccupations, and circumscribed, idiosyncratic, or special interests—cause notable disruptions in the functioning of autistic individuals, including those who are high-functioning (Klin & Volkmar, 2000; South, Ozonoff, & McMahon, 2005). Asperger (1944/1991; see also Volkmar & Klin, 2000) believed that the key aspect of excessive preoccupations is their interference with acquisition of skills in other areas, and, consequently, in adaptive functioning.

According to South and his colleagues (2005), excessiveness of interests could be evaluated in terms of their frequency, intensity, duration, or interference with adaptive functioning. From this perspective, the frequency (every day), duration (7–8 hours), and regularity with which Pierre pursues his interests (which is particularly obvious from his diaries) could be evaluated as excessive. Similarly, from the psychiatric perspective it could be argued that Pierre’s reading of Wikipedia and other Internet resources (that is, “collecting facts”; Hippler & Klicpera, 2003) or amassing factual information (Asperger, 1944/1991; Attwood, 1998; Gillberg, 2002; Tantam, 1991; Volkmar & Klin, 2000; Wing, 1981) might have been preventing him from actively seeking employment and acquiring the knowledge and skills necessary for a successful vocation, thus, interfering with his adaptive functioning. Likewise, Pierre’s interests could have been interfering with his learning age-appropriate social skills, thus, interfering with his social development and his ability to form close and intimate relationships in adulthood, as well as with his general life adjustment after schooling.

Although the above reasoning may appear plausible to a diagnosing psychiatrist (who practices within a medical model where special interests are considered pathological), it is important that Pierre does not perceive his daily engagement in a variety of interests as excessive, obsessive, or ritualistic. In fact, he, like many a layperson or humanistic psychologist, may object to such a view because it is these interests that are highly valued in academia and other occupational settings. When we consider that Pierre lives with a family where reading and knowledge acquisition is not only valued but lived and practiced every day, it becomes difficult to say that Pierre’s preoccupations with his interests are more unusual than those of his family members. In fact, Pierre’s assertion that his family considers him well adjusted may be taken as evidence against the above interpretation. As Tantam (1991) reminds us, “Although the obsessive nature
of many special interests is often their most salient feature, it is also a feature of normal interests in which it is, however, ‘forgiven’ because it is socially expected” (p. 162).

However, although the intensity of Pierre’s interests may be typical for his family, the fact remains that so far Pierre has been using the knowledge and skills he acquired, not as a means to an end, but as an end in itself. That is, were Pierre employed, supporting himself financially, and having more satisfying social relationships, how much time he spends in leisure activities would not be important. Because he is neither, it may be justified to label his interests as excessive on the basis that they interfere with his full adjustment to society and with meeting its expectations of him. Therefore, it is only in the context of his unemployment and lack of intimate social relationships that Pierre’s interests could potentially be regarded as pathological. That is, the judgment about the excessiveness of Pierre’s interests is dependent on the idea of normality in the culture in which he currently lives (for a discussion of this issue, see D. Murray, 2006).

In addition, Pierre’s interests and activities do not easily fit into a DSM-IV description for another reason: they do not appear to be restricted to a small number of more or less narrow areas, in that they include history, politics, mathematics, comics, puzzles, and several branches of art. Therefore, I conclude that Pierre’s daily reading and other intellectual activities are better viewed as a way of meeting his high need for cognition, as well as a way of providing him with enjoyment, structure, stability, and comfort. However, this view is not incompatible with the clinical view of autistic interests (e.g., Attwood, 2003; see also Bashe & Kirby, 2001; Gillberg, 2002) according to which special interests are a source of security, enjoyment, and anxiety reduction for autistic individuals. Discussing their relaxing and soothing properties, Attwood (2003) refers to them as a “natural antidepressant” (p. 136).

It is, however, important to note that information about Pierre’s interests was not obtained in the diagnostic context and that I do not have information about the diagnosing psychiatrist’s basis for Pierre’s diagnosis. That is, it is possible that in addition to the interests and activities Pierre told me about, he also has, or had in the past, some other behaviors that fit into DSM-IV classification more easily. One example of such interests could be his collecting of comics which he often mentioned in his diaries and on which he “spent several thousand dollars,” as he told me in a follow-up interview.)
9.3.2.2.1 Current Lives of Other Participants

Like Pierre, and as would be expected, most other participants who are currently not employed spend their days engaged in activities related to their interests. For example, Orville spends his days doing graphic work on the computer, listening to music, exploring nature and old railroads, and taking photographs. In addition to going to school, Jimmy also takes photographs and then edits and posts them on the Internet, reads, and listens to music. Geoff writes book manuscripts, listens to and makes music, attends baseball games, and goes cycling. Alan watches movies and TV, reads celebrity magazines, and listens to music. The 2 participants who work full time also spend some time engaged in their interests: Howard travels (with his father), attends and watches sports events on TV, watches other TV shows, and plays video games; and Mike participates in investigations and discussions about paranormal phenomena. (For a summary of participants’ main interests, see Table 9.)

It is interesting that all participants except Mike and Howard spontaneously mentioned listening to and/or making music and/or singing, and all except Sarah and Howard also mentioned reading—usually nonfiction (Pierre, Mike, Geoff, Orville, and Alan), although Pierre and Jimmy also like to read fiction. Another common interest among the participants was traveling; it was shared by 5 participants: Pierre, Geoff, Howard, Alan, and Orville. Mike also said that he would love to travel, but that so far he did not have much time to do that and that it is on his to-do list for his retirement. Five participants also mentioned watching TV and/or movies: Pierre, Jimmy, Alan, Sarah, and Howard. Four participants mentioned writing activities: Pierre (political essays, stories, diary, blog, Internet posts), Geoff (autobiography and a fiction book), Orville (poetry, Internet posts), Mike (articles on paranormal investigations). Three participants (Jimmy, Orville, and Howard) talked about taking photographs and two (Jimmy and Orville) about photo editing and digital processing of images. Jimmy and Orville also share an interest in nature, whereas Geoff and Howard share an interest in sports. Geoff and Orville have a joint interest in maps (subway and geographic) and an interest related to transportation (subways and abandoned railway lines). Several interests were unique to individual participants: Meetup groups (organizing and attending; Pierre); paranormal phenomena (reading about and
Table 9 Summary of Participants’ Main Interests

<table>
<thead>
<tr>
<th>Interest</th>
<th>Pierre</th>
<th>Mike</th>
<th>Orville</th>
<th>Sarah</th>
<th>Alan</th>
<th>Geoff</th>
<th>Howard</th>
<th>Jimmy</th>
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<td>(x)</td>
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<td>6(1)</td>
<td>4</td>
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<td>34(14)</td>
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Note. Parentheses indicate less intense interests at the present.

bThis information is based both on the interviews and diaries.

bInterests are ordered with respect to the frequency of main current interests, not their total frequency.

investigating; Mike); autism and philosophy (reading and discussing; Orville); calendars (reading; Sarah); celebrity magazines (buying and reading; Alan); and spirituality (Geoff). Finally, like Pierre, four other participants also either collected or still collect things: Alan currently collects celebrity magazines, and he used to collect toy action figures; Sarah collects calendars; Geoff used to collect music records and still has his collection; and Howard collects lapel pins.

As in Pierre’s case, none of these interests, except perhaps Alan’s, appeared excessive in the sense that they might have interfered with the lives of the participants. To the contrary, they seem to be sources of enriching their lives. For example, as in Pierre’s case, Sarah’s interest in music is an important source of enjoyment, as well as of pride in her skills and talents. She described her interest in calendars as follows: “I have calendars going back from 2001 till now,
and I usually look at each day of that year to see what I did. I usually do that at night time.”
However, although she does this every day, she does not believe that she would be upset “at all”
if she were prevented from doing it. This is, however, not the case with Alan who seems to have
a strong need for “buying magazines which cost me money, which I need for important things,”
and who expressed his inability to control it. As he put it,

I have to learn how [. . .] not to spend on magazines. That’s a big problem. I have a
tendency to buy magazines with pretty girls, where girls look pretty but [with] just
useless information which I don’t need.

Indeed, Alan’s descriptions of his several other must-do activities paint a very different picture
of his daily activities from those of other participants. Here is Alan’s description of one of his
many “obsessions,” putting his chewing gum out at a particular time, which, as already
mentioned, he has difficulty controlling and which is sometimes a source of problems in his
volunteer placement:

Sometimes I have to put my gum out at a certain time—[at the right] minutes and
seconds. [. . .] Like 3 seconds before the 3rd minute, like, 57 minutes and 17 minutes and
57 seconds, that’s mostly how I would usually put my gum out, there.

On the other hand, Orville, like Pierre, Sarah and other participants, described his almost life-
long interest in nature and his frequent hikes in the woods as a matter of choice, not an
obsession—he called it “bonding with nature”:

I don’t know whether the need to hike in the woods all the time when I was a teenager . . .
whether others might consider that . . . it was a choice of mine—it wasn’t an obsession—
I didn’t feel like something required me to get out into the woods. I just felt a sheer
bonding with nature when I went there. [chuckles]

Indeed, Orville talked a lot about his bonding with nature, which he described as follows:

And just something about nature always was [drawing] me out there to the grass and trees
and everything, and streams and following where the hills went, and all that—all the
time.

Orville also said, “I just could sit for hours and stare at the silhouette of a tree.” He also offered
an interesting observation for his ease of bonding with nature (in contrast to his lack of ability to
bond with people). He said, “Nature doesn’t require me to do anything to be bonded with it—the tree is just there, it’s accepting of me.”

**Observations.** When considering participants’ interests, it is important to note that participants’ mentioning and descriptions of them were often a) characterized by the use of words and phrases for emphasis (or for expression of intensity) and b) accompanied by changes in voice, speech quality, facial expression, and demeanor. For example, 5 participants used the word “love” in reference to their interests (usually accompanied by changes in voice loudness, quality, and, less often, in facial expressions): “I love music” (Pierre; follow-up interview); “[I] love the birds and trees” (Orville); “I really loved [playing in bands],” “my biggest love in life is music,” “my original love of music,” “I’ve always loved reading maps,” “I love subway maps,” “I love [. . .] figure[ing] out which trains and busses went where,” “I love traveling” (Geoff); “I love to travel” “I love my sports,” “I love photography,” “I love lapel pins” (Howard); “I like to take pictures—I’ve been doing that for about a year, and I love it,” “I’ve just always loved art and music,” “I’ve always loved music” (Jimmy). The participants also used other words and expressions such as “[it was] almost like my first spiritual experience,” “rapturous,” “excited.” (Geoff; in reference to his first listening to music on the radio); and “sport fanatic,” and “unbelievable” (Howard). Here is one relevant portion from the interview with Geoff:

G: My parents bought me a transistor radio for Christmas 1970. I was nine years old. [excitingly; looking happy; eyes glowing]
L: Oh, you look so happy now.
G: And, yeah, and I turned the radio on and, WOW! I absolutely . . . I don’t even know how to . . . I guess, the way I heard music, you know . . . when I first heard music it was almost . . . I wouldn’t have put in those terms then, but I look back on it now and it was almost rapturous, like, joyous, really, it was, sort of . . . I consider it almost like my first spiritual experience even though there is no . . . it’s not really by name but just listening to the radio, listening to all these songs, singing along, and, I guess, because of the way my brain is wired—I’m very verbal and auditory—you know, I would hear a song, and I would be able to listen to the whole song, but would also be able to pick out, Oh, look, this tambourine’s coming in right here over in the, you know . . . right in my headphones, right there. You know, I’d hear the tambourine coming and go, WOW, look at that. And I was just so excited. So I started buying records and . . . so, yeah.

Although Sarah did not use any specific words for her interest in music, except for perhaps the word “always” in “When I was a little kid, I always wanted to be a singer,” there was a change in
her voice when she talked about music. The same was true, with a more noticeable change in tone of voice and facial expression in case of Mike’s account of his interest in paranormal phenomena. Finally, Alan expressed the intensity of his interests in film and music by frequently using examples from these media in his answers. For example, he mentioned and/or described 15 movies (e.g., *Duma, Rainman, Basic Instinct, Pulp Fiction, and Natural Born Killers*) and 15 TV shows (e.g., *The Simpsons, MASH, Da Vinci’s Inquest, The Sopranos, and Larry King Live*); mentioned 6 characters from movies or TV shows (e.g., Incredible Hulk and Tony Soprano) and 15 actors and singers (e.g., Cameron Diaz, Michael Douglas, and Will Smith); and mentioned or recited parts from 3 songs (*Because I Got High, It’s the hardest thing I’ll ever have to do*, and *Sesame Street Subway*).

9.3.2.2.2 Interpretive Summary

In an effort to fulfill their creative and intellectual needs, as well as their needs for enjoyment, relaxation, and perhaps security, the participants of this study engage in a variety of activities: Whereas some of these activities and interests are also often mentioned in literature on autism (e.g., music, maps, calendars; see, for example, Atwood, 2006), some of them are unique to this group (e.g., Mike’s intense interest in paranormal phenomena, Geoff’s in spirituality, and Pierre’s in Meetup groups). Pierre’s interest in Meetups is particularly interested as it is the only social interest of higher intensity among the participants, and by definition, not characteristic of autistic individuals (Atwood, 2006). Moreover, in contrast to literature on activities related to special interests of autistic individuals (e.g., Atwood, 2006), activities of only one of the participants (Alan) appear to seriously interfere with his current social adaptation. Also in contrast to the literature (e.g., Atwood, 2006), which suggests that autistic individuals have a small number of interests, all except two participants (who had one or two main interests; Mike and Sarah, respectively), had 3 to 7 such interests.

Finally, the participants’ descriptions of their interests, together with their nonverbal expressions accompanying them, appear to point at one common feature that can apply to all participants: *passionate*. Thus, all participants appear to be passionate about at least one aspect of the world (cultural, physical, or even social): music (5 participants); photography, reading, and traveling (3
each); nature, arts, film, writing, and sports (2 each); politics, organizing, maps, autism, Meetup
groups, spirituality, and paranormal phenomena (1 each). Moreover, all participants also seemed
to have stayed loyal to what in most cases are almost life-long passions. Their use of special
words and phrases such as “always loved,” “rapturous,” “unbelievable,” “excited,” and “fanatic,”
and the changes in their nonverbal expressions indicated extreme levels of enthusiasm and
involvement. In fact, in most cases, participants seemed to have special relationships with their
fields of passion that were reminiscent of a sense of oneness, which Csikszentmihalyi (1990,
1993, 1999) calls autotelic experience, or flow, and is characterized by “concentration,
to Csikszentmihalyi, individuals who have such experiences relatively often, and who seek such
experiences for their own sake, are autotelic. (Literally, “autotelic” means having an end or
purpose in itself, from the Greek “auto,” for self, and “telos,” for end.) From this perspective
then, this study’s participants could clearly be described as autotelic persons.

9.3.2.3 On Pierre’s Social Life

As already mentioned, Pierre social life consists of relationships with his family members,
several casual friendships and acquaintances that revolve around common interests in arts and
politics, regular participation in several Meetup gatherings, regular engagements in community
projects and activities—that range from arts (singing in choirs and choruses) to politics (political
campaigns) to community gardening—as well as, most recently, virtual socializing on the
Internet. However, Pierre does not have any close friendships and romantic relationships, nor did
he have such relationships in the past. He said that he particularly enjoys exchanging his
thoughts and ideas on a variety of topics with others with similar interests through Internet
discussion forums. In fact, the Internet was so important for Pierre that he chose the year when
he connected to it as one of his most significant life experiences (which will be discussed in a
subsequent section).

Historically, Pierre’s efforts to improve his social life coincide with getting the autism diagnosis
and the completion of his PhD studies. His first efforts involved attending support groups
organized by local autism organizations. However, because these groups did not meet his social
needs, he looked for other socializing avenues. These efforts led to the discovery of Meetup groups, which appeared to be exactly what he was looking for—groups organized around common interests and not common problems as was the case with support groups. However, although he is happy with his participation in these groups because it meets some of his social needs, as well as provides him with socializing practice, it did not, as yet, result in any new friendships, as he had hoped for.

Based on this improvement in being more social, Pierre rated his social life as 3 out of 5, and said that he is hoping for further improvement, particularly in the area of romantic relationships. A girlfriend would raise the rating to 5.

9.3.2.3.1 Interpretive Summary

Pierre’s socializing pattern—that includes close relationships with family members and several casual friendships and acquaintances revolving around common interests but with no close friendships and romantic relationships—is consistent with literature on high-functioning autism (e.g., Attwood, 2006; Barnard et al., 2001; Howlin et al., 2000, 2004; Kanner et al., 1972). However, contrary to the popular misconception of autistic individuals seeking solitude and avoiding social relationships, it appears that Pierre has developed a keen social interest over the past several years. However, as already discussed, from his diary, it is difficult to discern whether his motive for the obvious increase in his social interactions is a genuine interest in others or an interest based on the knowledge that he should socialize more.

Pierre’s active role in his community where he volunteers in many of its projects is also consistent with literature, which suggests that other autistic individuals also often take part in community activities, usually related to their special interests (e.g., Dewey, 1991; Hurlbutt & Chalmers, 2002, 2004; Mercier, Mottron, & Belleville, 2000). However, Pierre’s participation in his community—that ranges from gardening to arts to politics—appears to be more varied than that of other autistic individuals, who usually take part in only one kind of activity.
Virtual socializing. Like Pierre, many other autistic individuals emphasized the importance of Internet for their social life (e.g., Dekker, 1999; McKeen, 1994; Shore, 2001; Sinclair, 2005; Tammet, 2006). Moreover, the importance of the Internet for autistic individuals has also been recognized in the popular media (Blume, 1997a, 1997b) as well as in the academic literature (Attwood, 2006; J. Davidson, 2008; Hacking, 2009a; J. Singer, 1999). Indeed, its importance is often compared to that of sign language for the deaf (Blume, 1997a, 1997b; Dekker, 1999; J. Davidson, 2008; J. Singer, 1999). For example, Blume (1997a) wrote,

The impact of the Internet on autistics may one day be compared in magnitude to the spread of sign language among the deaf. By filtering out the sensory overload that impedes communication among autistics, the Internet opens vast new opportunities for exchange.

Although for many non-verbal (low-functioning) autistic individuals “the Internet is Braille” (Blume, 1997b), for high-functioning autistic individuals, it is better characterized as an “ideal medium” of communication. As J. Davidson (2008) suggested, communication at a “socio-spatial distance,” like the Internet, is perfectly suited for “autistic styles of communication” (p. 801), for several reasons.

First of all, many autistic individuals have suggested that writing is their preferred way of communication. Expressing her own belief, as well as the beliefs of other autistic individuals who contributed to her anthology of autistic college students, Dawn Prince-Hughes (2002) wrote that “writing is the best way for an autistic person to communicate” because “it allows time to form one’s thoughts carefully, it has none of the overwhelming intensity of face-to-face conversation, and it affords the writer space to talk about one question or thesis without limit” (p. xiii). She later added that “I have said in the past, and I have since heard it repeated by other autistic people, that written English is my first language and spoken English is my second” (Prince-Hughes, p. 26). Indeed, many autistic autobiographers expressed, as Pierre did, their talents and passion for writing (e.g., Gerland, 1997; Hadcroft, 2004; Jansen, 2005; Kolinski, 1995; Miedzianik, 1986; Prince-Hughes, 2002).
Moreover, Martijn Dekker (1999) argued that because autistic individuals do not communicate much with body language and facial expressions, “autistic communication could be comparable to written communication.” From his first-person perspective, Stephen Shore (2001) explains why:

Cyberspace can be a good place for those on the autistic spectrum to meet others. . . . There are a number of reasons for the advantages of cyberspace to individuals with autism. The communication bandwidth is restricted to text. As a result, there are none of the nonverbal aspects of communication that so often present difficulties for those on the autistic spectrum. Also, there are no distractions of trying to remember what someone’s face looks like or what they might be trying to say via body language or tone of voice. Finally, if you no longer wish to communicate with a certain person, he or she can be ignored. (p. 142)

For all these reasons, the Internet is an ideal medium for fulfilling autistic individuals’ unique social needs. As Thomas McKean (1994) put it, it was a perfect solution because it allowed him to be “with others and alone at the same time” (p. 49). This unique and great advantage of the Internet has also been suggested by the Internet researchers. For example, Amichai-Hamburger (2005) also emphasized the Internet’s unique potential for mutually fulfilling the need to relate and the need for autonomy. Certainly, the ease of finding similar others in the variety of Internet venues, together with the sense of protection provided by the anonymity, allows autistic individuals, including Pierre, to easily fulfill their need for belonging (Bargh & McKenna, 2004). Moreover, it has also been argued that another benefit of the Internet for people who have social difficulties (such as introverts, socially anxious, and stigmatized) is that it allows them to develop and maintain relationships, both virtual and real (Amichai-Hamburger, 2005; Bargh & McKenna, 2004). In fact, the Internet has allowed many autistic individuals (e.g., McKean & Vincent, 2000; C. Mitchell, 2008; Tammet, 2006) to do exactly that. As Daniel Tammet (2006) put it, “there is something exciting and reassuring for individuals on the autistic spectrum about communicating with other people over the internet” (p. 155). Although Pierre once referred to people with whom he corresponded on the Internet as his “Internet friends,” it does not appear that he formed any personal relationships online.
For the above-cited reasons, the Internet is also a perfect communication medium for initial dating for autistic individuals (Hendrickx, 2008; Molloy & Vasil, 2002; Moxon, 2006). Indeed, several individuals met their dates or partners online (e.g., Molloy & Vasil, 2002; McKeen & Vincent, 2000; Tammet, 2006). However, although Pierre made some efforts in this direction, so far they have not been successful.

As mentioned earlier, the Internet also allows autistic individuals to connect with other autistic individuals for social support and to organize and advocate for better recognition (as a different way of being, not a disability) and acceptance by society (J. Davidson, 2008; Sinclair, 2005; J. Singer, 1999). Interestingly, Pierre never sought support from other autistic individuals through forums run by and for autistic individuals, nor is he involved with any autism rights movements.

Another benefit of the Internet for autistic individuals is access to information about autism. As J. Singer (1999) suggested, this is extremely important in that it gives autistic individuals a sense of empowerment. In addition, Blume (1997a) suggested that the Internet also has an important role in displaying “an altogether different side of autism” than one presented by science:

> In cyberspace, many of the United States’ autistics are doing the very thing the syndrome supposedly deters them from doing—communicating—often in celebration of the medium that enables them to do so.

> “Long live the Internet,” one autistic recently exulted in an online discussion, where “people can see the real me, not just how I interact superficially with other people.”

### 9.3.2.3.2 Social Relationships of Other Participants

**Alan.** Like Pierre, Alan has good relationships with his parents and his brother, as well as his aunt who lives next door. Like Pierre, he also has three friends (one of whom is autistic—more severely than he is). Asked to describe his socializing with his best friend, whom he sees “once every 2, 3, 4 months,” he replied, “sometimes [we] watch a bit of TV, or eat lunch, [or I] show him some interesting magazines.” Like Pierre, Alan is also engaged in community activities, doing office and other work with a local non-profit organization. He also performs with a drama
group. Like Pierre, he never had a romantic relationship. Also like Pierre, he rated his social life as 3, which he justified as follows: “Cause sometimes it’s good, sometimes it’s not so good, so it’s on the average, here.” In order to improve the rating, Alan said, “I should try to make more friends [with] other people who are sometimes not as autistic as I am. But it’s not so easy.”

Sarah. Like Pierre, Sarah also has close relationships with her family (which includes her parents and a brother). She said, “I like spending time with my family,” which she described as “loving” and “supporting.” When asked what could never change about her life, she replied, “Well, that I always have this part of my family.” Like Pierre, Sarah also has three casual friends (all with learning disabilities), whom she had met at college and whom she has known for about 6 years. She sees her friends several times a year; she described their interactions as follows:

We would usually go watch movies at one of their place or go to a movie, stuff like that. Well, I would celebrate birthdays with them. So usually that would involve either going out to dinner with them and their family. One of my friends has a cottage up North, so I usually go up with her.

In the meantime, Sarah stays in phone and Internet contact with her friends. Like Pierre, Sarah also sings in a choir, except that she sings in a church choir every Sunday. Also like Pierre, she never had a romantic partner. However, in contrast to Pierre, she has additional social contacts at her two places of work. Also in contrast to Pierre, Sarah rated her social life as 5 and claimed that it does not need any improvement.

Howard. Like Pierre, Alan and Sarah, Howard’s main social relationships are with his family. As already quoted, Howard said that his favorite friends are his parents. Howard’s additional social contacts are through the two interest groups to which he belongs, as well as through his work and his volunteer activities. He calls one member of one of these groups his friend, and he sometimes, although rarely, sees him outside the group meetings and also sometimes exchanges e-mails with him. Like Pierre, Alan, and Sarah, he has also never had a girlfriend. Nevertheless, like Sarah, Howard rated his social life 5. He confirmed his rating in words: “It couldn’t be better.” Like Sarah, he also claimed that he does not need more friends than he currently has nor a romantic relationship.
**Jimmy.** For Jimmy, like for Pierre, Alan, Sarah, and Howard, family relationships are currently the most important social contacts. Jimmy described his relationship with his mother as “pretty good” and with his sister as “good,” but not very close. Nevertheless, when asked what could never change about his life, he said, “My mother and sister would always be in it.” When asked about his current social life, he replied,

> Almost non-existent. I go to class during the day, I come home, and I just [pause] sit there, pretty much. I have, like I said, one friend that I see occasionally, which would be just going to his house and sitting there [. . .] mostly watching TV, playing video games. I do have friends from the restaurant industry. I’ve been trying to sort of reconnect with people more lately, my friends that own bars and restaurants near where I live. So I try to go out and force myself to go occasionally, but that’s me going out by myself, so I usually just go and sit there, you know. And if someone I know is working there, if they have time to talk to me, it’ll be, sort of, sporadic, but . . . that’s about it.

Asked to characterize his friendship with the person he called *friend*, Jimmy said, “I would consider him a close friend only because we’ve known each other for 20 years, but I don’t think he really knows me very well.” Although he visits his friend once a week or so, he said, “It’s more like just kinda change of scenery. Just to get out of the house.” He also said, “I enjoy the company of other people, but I don’t have any strong bonds with anyone.”

Although Jimmy, like Pierre, Alan, Sarah, and Howard, did not have a romantic relationship at the time of the interview, in contrast to these participants, he had had several such relationships in the past. During his last such relationship, which lasted “couple of years” and ended “6 or 7 years ago,” he also lived with his girlfriend. Unlike other participants, Jimmy does not have any group relationships because, as he put it, “I don’t do groups.” Likewise, although he had been attending school for several months at the time of the interview, he did not form any relationships with other students. Most recently, however, Jimmy, like Pierre, started using the Internet to socialize with others, in his case, with those who have an interest in photography.

**Geoff.** On the other hand, although Geoff has a good, but not close, relationship with his brother (his parents are not alive), and also has three people whom he calls friends (one of whom is autistic), and has some volunteer engagement with an autism-related project, his main social contacts are thorough two interest groups (as already described). Asked to describe his social life, he replied,
I’d say it’s more active than it’s ever been, which is good. But it’s still probably pretty limited. I have [long pause] . . . I have [Eagles] group I go to, every Monday night, [long pause] and I consider them my friends. They are all quite a bit older then I am.

Although like other participants, Geoff did not have a romantic relationship at the time of the interview, nor had he had one for the past several years, like Jimmy, he had had romantic relationships in the past, including being married for 8 years. It is interesting that, like Pierre, Geoff also used the Internet as a means of establishing new romantic relationships. However, unlike Pierre who attempted to use dating websites, Geoff developed his relationship through a support group website, and, unlike Pierre, he was more successful in it and was able to establish one long-distance relationship, which, however, fell apart after a first face-to-face meeting. Finally, unlike any other participant, during the interview, Geoff also talked about his spiritual relationship with his dead female cousin—whom he loved but the love was not returned. In fact, he talked more about this relationship than about the rest of his real life relationships together. He described his first meeting with his cousin as the most disappointing experience of his life:

When I first met my cousin, who later died and all that, okay, and [pause] I was madly in love with her, but, you know, again, there was this age difference, I was really awkward, I didn’t know what to do, and I ended up writing her a letter telling her that I loved her and so on, and she wrote me back, and said, “No, I’m sorry,” you know, “I’m sure someone will love you someday, but I’m not that person.” And I was crushed, and I was suicidal for the first time.

Geoff also described how when he was 31, he “forged a connection” with this dead person, who “became like a guardian angel to me or a spirit guide, so she now is like a centre of my spirituality”:

This was my cousin—I fell in love with her. It didn’t work out—I was devastated. I sort of went off and try to get over her, and then much later, 11 years later, 10 years later, she died. And she was 24 at the time, and I didn’t hear about [it] right when it happened, I heard about it three weeks later, and I was devastated, and I was shocked, it was like my wife had died or something, it was really . . . what I felt I could not believe and I wanted to . . . I had this sort of overwhelming feeling that I wanted to help her, sort of make the transition, you know, into the afterlife, that sort of thing. So my parents were kind enough to drive me, this was a rainy labor day Monday, I’ll never forget it, and my parents drove me to the cemetery which was in [Mont Blanc], and I just, you know, sort of prayed and chanted and it was really something. And I think, you know, I felt a little bit of relief after. [. . .] The biggest thing that happened really was [long pause], I came to realize
later on, that by doing what I did, I have, sort of, forged a connection with her. And so [ . . . ] what happened was is I ended up getting sort of a guardian angel out of it. And so this relationship began and it’s changed my life completely.

Geoff rated his social life 4, and explained, “Compared to all the other people, I don’t have a real active social life, but I don’t really need one.” Nevertheless, unlike Sarah and Howard, he would like to have a girlfriend.

**Orville.** Orville’s account of his social relationships is both similar and dissimilar to those of others. Like others, he has a good relationship with one of his sisters (his parents are not alive); however, his main social relationships, to which he referred to as “smaller friendships” and “loose association,” are with several people who he calls “close associates [ . . . ] but not [in the] sense of partners that I was talking about, the other sense of deep bonding,” with whom he has philosophical discussions, usually at place of their work. When describing these relationships, he said, “And they run a store, actually a gas station variety store here in town, sort of, like, a hangout for me where I can go in there and speak to them.” He added,

> And one chap that works at the store there on weekends—he’s about 24 now . . . I helped him out . . . a lot of mentoring to do with his studies [ . . . ] And he and I had been able to discuss a lot of things that are beyond chitchat, like into philosophical issues—why some things such as trees can be so important, and that.

Like all other participants except Jimmy, Orville also made several attempts at joining local interest groups (e.g., writer’s, naturalists, and bird watcher’s club); however, he did not find those experiences very enjoyable and currently does not belong to any such group. He compared his feelings about his current “loose associations” with those he had in groups as follows:

> I say “loose” in that I had to practically invent it myself, whereas I couldn’t go [taps table] to [taps] an organization [taps] and feel the same sense, whether it’s a writer’s circle, whether it’s a naturalists group, or whether it’s some other association around. [ . . . ] And, it’s been times when I have gone into group and then there’s been disagreements arisen to the point where I felt that I couldn’t even associate with the group anymore.

Although like all other participants, Orville did not have a romantic relationship at the time of the interview, he established one such relationship by the end of the study, and he, like Geoff and Jimmy, had had one such relationship in the past, which he established over the Internet:
And that’s the only thing, I’d say, that has helped in the last while has been the Internet itself, whereas without the Internet, I had to do everything locally, and that was a lot harder. But at least now, with the Internet, you connect more globally, and that’s how I met that lady I say from [US state], there.

Orville’s virtual relationship survived the reality test, unlike Geoff’s, and lasted for several years—until that person passed away. Nevertheless, Orville also experienced a change in the relationship after the initial face-to-face encounter. As already mentioned, he felt that there was a lot of misunderstanding of each other’s differences—on both sides—and not enough accepting of him as he is. For example, Orville felt pressured to change and behave like “most normal males” and to change his “bad habits” that were beyond his control: “[She] was always telling me, ‘Stop biting your nails,’ and everything, all the time.[ . . .] And even when I was driving, or something, I was doing it, and she was saying, “Stop that right now.” He said that at those times “[communication] seemed to break down.”

During the interview, Orville also described in some detail his virtual relationship with another woman; by the end of the study, this relationship was transformed into a real romantic relationship. Orville also said that “now and again” he “meet[s] people [and] chat[s] with [them] on the Internet,” and he also communicates with others over the Internet regarding autism-related issues. He participated in several discussion groups on the topic but after having some unpleasant exchanges he stopped participating.

Orville rated his social life a 2. He elaborated on his answer as follows:

So it’s those smaller friendships [with people who own the store], I say, [that] are my greatest assets right now on a scale of two. If I’ve said “one,” I’d feel like a person who didn’t have any friends anywhere, [laughs] see. So I’d say at least I’m up to two with these few other people [to] whom I can go, and they don’t mind me staying around the store. They are not like some people saying, “Do you want anything else sir?” If I don’t, “I kindly ask you to leave the store.” [laughs]

Orville also elaborated on what would have to happen in his life for him to raise his rating:

More intimacy. Closeness with other people is one of the main things, I would say, so that I can feel more part of the community. […] If I did have a partner in life […] even a person that lived, say, in [Newmarket], and I lived here, but we could still be partners
some way, there. [That at] least, I’d say, would be step up to at least put me to level three out of five. But then, if I can get more involved in, let’s say, the community, say, in environmental issues, like, where people wanna protect the land from development, say, and put a park or something in that way, that would even be another step upwards. I always remember a chap [ . . . ] And I thought, Boy, I wish I could climb up socially like he did. From being almost an unknown person to being a person who’s getting a full pension after being two terms in office. [ . . . ] So it’s, boy, I think that would put a person right up to five then, and he had a partner already. [laughs]

Mike. Mike’s social relationships were the most varied of all participants. At the time of the interview, he was the only participant who was in a marital relationship (at least formally), who had a “co-parental” relationship with his wife, parenting relationships with his two children, as well as professional relationships at work. Yet, when asked to describe his social life, he replied, “I am trying to establish a social life.” Asked whether he has friends, he said, “I don’t, other than the next door neighbor” and added,

I socialize with him because he is our neighbor, but it’s more because they’re friends, his wife is my wife’s friend, that’s why. She mainly makes the friends. Do I have any friends? I’ve had friends in the past, but I’m not in contact with them . . . a couple of friends, but I don’t have any friends, I don’t. I have no friends—none.

As already described, despite being formally married, Mike had not had intimate relations with his wife, for at least the last several years. However, like Pierre, Mike also recently increased his efforts to establish new friendships by finding people with similar interests, and, like most other participants, he also recently joined two hobby groups. It is also interesting that, like Pierre, he also found Meetup groups that he starts a potentially useful avenue for establishing friendships. Mike said, “I am making an effort to try and build some friendships like with this [paranormal] group and the other one I am involved in, that’s more cyber.” He added,

I think, I can find different ways of making friends . . . that are . . . people with similar interests as me. I think, if I put an effort into it, as opposed to concentrating on myself, I think that might be the key. I may not have a great amount of success, but I think I could—but finding those interests that I do have, and finding a way to expand them, so I can welcome other people in as I set one of these Meetup groups that I start—not a support group. [ . . . ] And, that would be probably a way I could, maybe, meet some other people—both women and men.
Asked to rate his current social life, Mike said, “Probably around one. One, one point five maybe, because I’m including the neighbors and family. Hopefully that’ll go up a little bit, I’m hoping.”

9.3.2.3.3 Interpretive Summary

Most participants had a pattern of social relationships similar to Pierre’s. (For a summary of this information, see Table 8.) Family relationships were either important or the most important part of the social lives of most participants. Like Pierre, none of the participants reported having a really close friend. It is interesting that, like Pierre, three other participants said that they also had three casual friends (Sarah, Alan, and Geoff), which was the highest number of friends reported by any participant. These friendships involved spending time in mutually enjoyable activities such as watching movies, going out for lunches, celebrating birthdays together, talking, and communicating over the Internet. It is interesting that although Orville had casual relationships with more than three people, he was aware that these people allowing him to come and “speak to them” and “let[ting him] drop in any time” was not what is usually considered a full friendship and he referred to these relationships as “smaller friendships” or “loose associations.” Likewise, Jimmy also mentioned going to a place of work (i.e., restaurant) of people with whom he used to work, and to whom he also referred as friends, and trying to talk to them “if they have time to talk to me.” In addition to these contacts, he, like Howard, considered only one other person a friend (with whom he also had a more restricted type of socializing than other participants, such as one-way visiting, watching movies, and playing video games, but not much talking).

Only 1 participant (Mike) reported not having any friends. Like Pierre, none of the participants had a romantic relationship at the time of the interview, and like Pierre three other participants (Sarah, Alan, and Howard) had never had such a relationship. Moreover, none of the 4 participants who had had such relationships in the past (Mike, Orville, Geoff, and Jimmy) reported having a particularly romantic, intimate, or close relationship. Indeed Mike was the only one who said that he loved both his wife and his first girlfriend. Finally, like Pierre, all other participants except Jimmy and Orville were involved in group socializing (e.g., Meetup, sport clubs, and autism support groups).
It is also interesting that all participants except Alan mentioned using the Internet for socializing. However, whereas Sarah and Howard mentioned using it to communicate with their friends and relatives, Pierre and four other participants (Mike, Orville, Geoff, and Jimmy) used the Internet for the purpose of socializing with strangers. As a person living in a small town which does not provide many opportunities for someone like him to readily find people with whom he can socialize, Orville was particularly grateful for the Internet which allowed him to communicate with people all over the world, and even to establish some friendships and romantic relationships. However, Orville made it clear that Internet communication in itself is not a panacea for autistic people’s social difficulties because it does not help much with one-to-one real life situations.

Like Pierre, all other participants in this study, except for Orville and Jimmy, have an active role in their communities where they volunteer in many projects. However, unlike Pierre, who participates in a wide range of projects, all other participants are engaged in one or two projects or activities. These activities included singing, drama, office work, and fundraising. It is also interesting that although Orville was not involved in any community projects at the time of the interview, he spontaneously expressed an interest in such projects.

In contrast to these similarities, participants largely differed in their subjective ratings of their social lives and used six different ratings ranging from 1 to 5 (one rating included half a point). Only Alan estimated his social life as Pierre did, at the middle point. Three participants rated their social lives lower than Pierre did: Jimmy, 1; Mike, “1, 1.5”; and Orville, 2. Likewise, three other participants rated their social lives higher than Pierre (and Alan): Geoff, 4; and Sarah and Howard, 5.

These ratings also point to the contrast between subjective and objective perspectives on social life. Thus, whereas from an objective, third-person perspective, Mike’s social life would be considered the richest because he was married, had children, was employed and had many acquaintances at his work, socialized with his next-door neighbor, and participated in two hobby groups (one of which was virtual), he rated his social life the lowest or next to lowest of all participants (“1; 1.5”). In fact, Mike’s rating was only slightly better than Jimmy’s (1), who in
addition to his mother and sister only reported socializing with one more person on a relatively regular basis, but with whom he did not have a particularly strong nor rich relationship.

On the other hand, Howard, who never had a friend outside his hobby groups nor a girlfriend, rated his social life as perfect and said that it could not be any better; that is, it met his needs. His evaluation resembles that of Temple Grandin’s (1992), whose social contacts are all related to either her work or autism but who is happy with that kind of social life because it suits her needs.

My life is my work. If a high-functioning autistic gets an interesting job, he or she will have a fulfilling life. I spend most of Friday and Saturday nights writing papers and drawing. Almost all my social contacts are with livestock people or people interested in autism. (p. 123)

This point was also made clear by Geoff: he rated his social life 4 and said that he would not want more social relationships than he already had (except for a girlfriend). However, from the third-person perspective, his almost exclusively formal group socializing (with the exceptions of occasional outings with one casual friend and rare exchanges of emails with other two, also casual, long-distance friends) would be considered far from satisfactory. It is important to note that Wing and Gould (1979) also found extraordinarily large differences in the social needs of autistic individuals, ranging from very low to very high.

9.3.2.4 On Pierre’s Self-Evaluation of His Adjustment to the World

Pierre believes that he is well adjusted to the world, but not perfectly. Accordingly, he rated his adjustment 4 out of 5, and expressed his belief that for a perfect rating, he would also need to have a job and a girlfriend. It is interesting that these two missing pieces, having a job and a romantic partner, are among criteria usually used in outcome literature in the field of autism, as well as among criteria used by lay people.

9.3.2.4.1 Other Participants
Sarah and Howard. Like Pierre, Sarah and Howard felt that they were well adjusted, but unlike Pierre, they did not find anything missing from their lives and felt that they were as well adjusted as they could be. Accordingly, they rated their adjustments 5. As Sarah put it, “just having friends, accomplishing school, and hav[ing] a nice family life” made her feel that she was well adjusted. On the other hand, Howard believed that he is well adjusted because he accepted his autism and learned to live with it—the best he could: “I learned to live with autism. I just lived the way I can. I don’t know any other way.” In addition, he expressed his belief that he was doing better than many people predicted: “I did a lot better than most of my teachers ever would have [predicted I] would. [. . .] They didn’t have high hopes for me.”

Orville. Orville also believed that he was well adjusted, although to a lesser degree than Pierre, Sarah, and Howard, and rated his adjustment 3. Here is his reply to a question whether he considers himself well adjusted:

I would say yes, in the sense that, like, I’ve said before, I haven’t ran into trouble with the law all these years, driving record, never been [troubled] other ways, even worked with people from different backgrounds, and that, but the only [unsatisfactory] adjustment, again, I keep reiterating, is this lack of bonding with other people.

As he said in response to the question about liking himself, Orville said that he would consider himself better adjusted if, in addition to social bonding, he also had some “community influence” because “I’d like to have an influence on others.”

Alan. It is interesting that Alan, for whom being well adjusted meant “learn[ing] some different things, try[ing] new food,” also rated his adjustment 3, but in response to the question whether he considers himself well adjusted, he replied, “No, not really. [. . .] Sometimes I am, sometimes I am not.” He said that “it’s just hard to fit, it’s hard to adjust,” because he needs to learn many things about living by himself “[in] my own house and my own place,” which he finds difficult to learn. For example, he said,

You can cook whatever you want, but [you have to] know when to cook good meals for self, when is a good time to have food even if it’s already prepared, like frozen food, or something, like instant soup, and things like that.
Geoff. Like Orville and Alan, Geoff also rated his adjustment 3, but when asked whether he considered himself well adjusted, he, like Alan focused more on why he does not consider himself fully adjusted, including the obstacles that are part of the world in which he lives:

In some ways no, I don’t. I feel . . . [long pause] I do feel a bit like an alien in this world and I don’t in general find it very welcoming. I think I’ve learned to get by okay, but I very rarely feel [long pause] that I am part of society and that the society embraces me, I’m hoping that can happen someday, but I don’t feel that way yet.

In justifying his rating of 3, he said,

I think [pause] I seem to be able to function in the world relatively okay, which is good, and I don’t feel persecuted, you know, like, everybody hates me, or anything like that. In fact, a lot of people really like me, so that’s good. But I do sense that very much, you know, that on almost any topic, if the majority believes this, I’m always the guy over here. Always. So there’s, again, that persistent sense of, you know, swimming against the tide, or that I’m different.

Jimmy. Jimmy, for whom being well adjusted means being “able to get-by day to day life and be happy,” felt that saying that he was well adjusted “might be a stretch.” He rated his adjustment accordingly: “2, 2 to 3.” He said, “I had to learn, sort of, to adapt [. . .] how to be”:

I can force myself to go out and do things. I’m not sitting in the room by myself all the time. And I can communicate with someone one-on-one. Group situations are still difficult. I mean, just . . . I guess, just the general anxiety, and fear and, sort of, [to] be more motivated to do things.

Mike. Unlike all other participants’ ratings, Mike’s rating of his adjustment was in a clear “not-adjusted” zone: “1, probably 2.” In response to the question about being well adjusted, he replied, “Well, I fit in, I don’t fit in, but I . . . am I well adjusted? Uugh, not really.” He explained, “Well, obviously I’m not well adjusted because I’m not accepted.” Indeed, he suggested that being accepted and “being happy” are the main indicators of how well someone is adjusted.

9.3.2.4.2 Interpretive Summary
The participants’ evaluations of their adjustments ranged from 2 to 5, out of 5. According to numerical evaluations, all participants except Mike, considered themselves more adjusted than not, rating their adjustments from 3 to 5 (although Jimmy’s rating was not a “clean” pass: “2 to 3”). However, closer examination of participant’s justifications for their ratings reveals that only 4 participants were unambiguous in their positive estimations (Pierre, Sarah, Howard, and Orville). Consistent with their self-evaluations, Sarah and Howard, did not find any faults with their adjustments rating them 5 out of 5.

However, although half of the participants rated their adjustments 3 out of 5, their open-ended evaluations given in reply to the question whether they considered themselves well adjusted included a range of responses that meant both yes and no: “yes” (Orville); “No, not really” (Alan); “In some ways no, I don’t” (Geoff); and “[well adjusted] might be a stretch” (Jimmy). Therefore, according to these open-ended evaluations, it appears that only Orville had no doubts about his good adjustment, thus joining Pierre, Sarah, and Howard in the group of participants who considered themselves well adjusted. On the one hand, Alan, Geoff, and Jimmy seemed to believe that they were more maladjusted than adjusted—but relatively close to good adjustment. Unlike these participants, Mike felt that he was nowhere close to being well adjusted, which he expressed accordingly in both his numerical evaluation and descriptive evaluations: “1, probably 2,” and “Uugh, not really,” respectively. Mike’s low self-evaluation is particularly interesting because it represents the biggest discrepancy from the objective criteria of social adjustment (i.e., employment, marital, and independent living status), according to which he would undoubtedly be placed in the well-adjusted category. In fact, based on these criteria, he is the most well adjusted participant in this study.

It is particularly interesting to compare Pierre and Mike’s views on their adjustments. Thus, Pierre, who rated his adjustment 4 (“Well adjusted”) said that if he had a job and a girlfriend, he would have rated it 5. On the one hand, Mike, who already had a job and a wife (although at the time they were not in a particularly close relationship), still felt far from being even close to being somewhat adjusted (“1, probably 2”: “Uugh, not really”). However, the difference between these evaluations is easily explained when we consider the criteria of adjustment on which they were based. Thus, whereas Pierre adopted societal criteria (i.e., job, partner) as his own, Mike used his subjective criteria—his feeling of (not) being accepted. (He said, “Well, obviously I’m
not well adjusted because I’m not accepted.”) However, as the above analysis suggests, what was obvious for Mike, was not so obvious for others, including other participants in this study. In fact, only Orville and Geoff considered acceptance as an important factor when they evaluated their adjustment. Interestingly, although Geoff believed that many people like him (perhaps those who know him well), he still felt not welcomed by society because of his different way of thinking, which makes him feel like an “alien.” Orville also expressed his feeling of not being welcomed by the society in even stronger terms—he often felt rejected.

The above comparisons point to the importance of considering subjective views on adjustment, which was also recognized by Orville, who presented his view on the issue as follows:

*Degrees of importance can be so relative* to a person. At one moment something might be *very* important to *one* person, but [. . .] even though this issue, or this idea, or this problem is *very* important to you, it doesn’t mean it’s important to *everybody* and vice versa. What is important to *somebody* else may *not* be important at all to *you*, but each person has to be [. . .] *respected* for his *feeling* that something is important [. . .], [and] *nobody* should be able to *dictate* importance no matter who they are.

Orville made another important point about adjustment when he said that other people consider him well adjusted because “I more than compensated for any *deficits* that I have [. . .] So that’s how the adjustment seems to be, as almost the *assets outweigh* the deficits.” He then gave an example of a deaf person who compensated for his deafness with his strengths and suggested that the same applies to autistic people:

The same with autistic people, not *whether* they can socialize or not as a part of adjustment, it’s adjustment in recognizing that they can’t socialize to the *degree* that *normals* can, but why keep trying to concentrate on *that part* without concentrating on the *good* side of them.

Sarah also made an important point regarding yet another aspect of relativity of judgments about adjustment (although in response to an unrelated question about her diagnosis). She said, “Now I know who I am, how much I’ve accomplished. I’m feeling quite proud of myself.” I believe that Sarah’s statements remind us that any judgment about adjustment is incomplete, and thus inadequate, if it does not take into account how much the person accomplished with regard to a previous point of reference for that person, not with regard to universal standards. (This point was also made by Orville who said that he can only be compared to himself.) This point was well
illustrated by Jimmy’s account of his adjustment when he said that he considered that now he “can force [him]self to go out and do things,” which meant that before he could not do that. He also said that he is “not sitting in the room by [him]self all the time,” which means that that was what he was doing before. Indeed, he talked about “learn[ing] to adapt,” by which he meant learning and applying rules and strategies about everyday life that do not come naturally to him.

Likewise, Alan considered all the things he learned about cooking and other activities necessary for independent living, including not only how to prepare food but also “when it is a good time to have food even if it’s already prepared,” which not too many people would consider an accomplishment because they did not have to learn it—knowing when to eat comes naturally to them as does knowing when to go out and socialize. In addition, Alan’s list of things that he still has to learn includes many not-to-do items that never make it to other people’s lists of life accomplishments, such as not having to put out chewing gum at a particular minute and second, not to talk to random female strangers on the street as if he knew them, not to buy any and all celebrity magazines he sees on news-stands, and not to overwhelm conversations with too many details—particularly not with details about the “big bad world.”

Jimmy and Alan’s examples of their life accomplishments point to the inherent difficulty of determining adjustment with the same measuring stick for everybody and point to the need to develop new, dynamic and individualized, measures that take into account the obstacles people had to overcome before they achieved a particular end point. It is interesting that although this problem is well recognized in many areas of life, it remains unrecognized in the science on life outcomes. Take sport, for example: nobody would consider a race valid where every athlete would run different distances and jump over different hurdles; yet, this is exactly the case with life outcome studies of autistic people.

Another important point made by participants in this study relates to their feeling of others’ expectations (including those of the society as a whole) that they have to change in order to be accepted or regarded as being well adjusted. This point was made by most of the participants throughout the interview (i.e., not necessarily in the part when they were specifically asked about their adjustment). In fact only Sarah, Howard, and Jimmy, did not make such references, fully accepting that they are the ones who need to change.
Like Pierre, Orville, Mike, Geoff, and Alan, other autistic individuals made similar points. For example, Dominique Dumortier (2004), who believes that “[she has] tried hard enough to adapt, but that ‘total’ adaptation just isn’t feasible,” (p. 87) wrote,

I want to be able to be who I am.
I get the feeling that I constantly have to adapt to the world when I can’t. I simply don’t have the ability. I don’t understand “the” world and nobody understands “my” world. I often get angry with myself and hope I will finally have learnt how to act and think differently. But that never happens. I want things to be different! (p. 88)

### 9.3.2.5 On Pierre’s Life Satisfaction

Pierre seems to enjoy and like his life as it is and finds only two things missing from it: a job and a girlfriend. If he had them, he felt that his life would have been perfect. Without them, he still rated it 4 out of 5, the same as he rated his adjustment.

#### 9.3.2.5.1 Other Participants

**Sarah and Howard.** Like Pierre, Sarah did not make any distinction between life satisfaction and adjustment, rating both 5, for the same reasons (“having friends, accomplishing school, and hav[ing] a nice family life”). (Sarah’s already-quoted statement that she likes herself because she enjoys her life is also relevant here, as the subsequent discussion shows.) On the other hand, Howard, who also rated his life satisfaction 5, explained his rating through his enjoyment of life: “I enjoy life. I take it every day the way it is. I take everyday life one day at a time.”

**Orville.** Like Pierre, Orville also rated his life satisfaction 4 out of 5, a point higher than he rated his adjustment. He explained,

I’d say that [I’m] not too dissatisfied because my health is been good all these years, that’s one of the main things. But all the problems other people are going through as far as health around me . . . every day I’m running into people complaining about their legs or about back, or everything else, and I’m thinking, Boy, I’m sure one of the lucky ones—hardly ever visit a doctor and so on. And [I’ve been] lucky, all these years [I’ve] been driving, no major accidents or anything. And [I] can come and go when I feel like it,
got a home of my own and living in a quiet community [. . .] I rather live here than in [Montréal] [. . .] And [I] still have sisters and brothers alive, and have these few friends around me I can turn to, and [I] love the birds and trees, and still could go exploring for abandoned railway lines. So I could say the only thing [that] seem[s] to be missing is that other partner to share this life with. [. . .] And I feel [. . .] as though life is wonderful, but the partner’s not, [chuckles] is sort of the feeling I get. So that’s why I say on a scale 4 out of 5, really. But again, it would have to be a partner that does understand these things about nature, and that, not somebody who would constantly be nagging at me to go and join them and . . . say cricket league or something else like that. [chuckles]

Alan. Like Sarah and Howard, Alan also rated his life satisfaction the same as his adjustment (3); however, he justified it differently:

I like most of the things, like, seeing a good movie or hockey games or doing . . . accomplishing things. Accomplishments like cooking good food. Besides cooking some good food, [I] like playing [and] winning a card game or doing some good job at home, like vacuuming, or things like dusting. I clean my bathroom. I know how to clean my bathroom as well before I move to [inaudible]. I learned how to clean the bathroom, there, small bathroom. It’s a little bit tricky, there, because the space is small, but I got used to it for now.

Geoff. Geoff also rated his life satisfaction 3, the same as he rated his adjustment, but qualified his answer by saying, “I think that’s being a bit generous but, three.” He provided the following justification:

I’ve actually [pause] drawn up a little chart, which is very, you know . . . we [autistic people] tend to do this, right? And I thought about where am I at jobs, health, home, relationships: Home, I’m doing okay; health I’m not doing too badly; jobs right now are a disaster, and relationships are a disaster.

When asked what his life should look like to deserve a rating of five, Geoff said,

Five would be [long pause], ideally, that my book be published, that it would do well, that I could earn a living from writing, and that I could be in a good relationship, and maybe eventually move to a nicer place than I’m living in now.

Mike. Interestingly, like Orville, Mike also felt a bit more satisfied with his life than he felt he was adjusted and rated it “about 3, I guess, 2, 3.” He explained his rating by reference to acceptance, as he did for adjustment.
**Jimmy.** Jimmy rated his satisfaction the lowest: 2, which is slightly lower than his rating of his adjustment (“2; 2 to 3”). He said, “Well, it could be worse. [chuckles] I know I’m lucky in a lot of ways. […] I have family and [pause] a hobby. [pause] I have somewhere to live, I’m not starving.” Asked what would make him more satisfied, he replied, “Friends. [long pause] A job I like. […] Something more on a creative side, I guess. I get a lot of satisfaction from creating something.”

**9.3.2.5.2 Interpretive Summary**

All but one participant of this study reported being relatively satisfied with their lives: Two participants rated their life satisfaction 5; 2 participants rated it 4; another 3 participants rated it 3, and 1 participant rated it 2.

As in the case of adjustment, Sarah and Howard estimated their life satisfaction at the highest level (5). Like Pierre, Orville also rated his life satisfaction 4, which represents a slightly higher rating than he gave to his adjustment (3). He also gave slightly different justification for life satisfaction than for his adjustment, which, in addition to adjustment factors, also included health, a good driving record, having brothers and sisters, leisure activities (exploring nature and abandoned railway lines), and a place to live (his own home in a small community which he prefers to a large one).

Three participants (Alan, Geoff, and Mike) occupied the middle zone of life satisfaction, rating it as average (3), which is the same rating they gave to their adjustment. However, whereas Mike cited the same reasons as for adjustment (i.e., level of acceptance), Alan and Geoff made their estimations of life satisfaction based on criteria different than those for adjustment. Thus, in addition to accomplishments related to independent living, such as cooking and cleaning, Alan also considered the enjoyment he associated with his leisure activities, such as watching a good movie or a hockey game, and playing and winning card games. Likewise, Geoff’s criteria included employment, health, housing, and relationships—none of which he specifically considered when he rated his adjustment, largely based on his feeling of not being welcomed by society.
Only Jimmy expressed unambiguous dissatisfaction with his life, rating it 2, which represents a slightly lower rating than for adjustment where he was somewhat ambiguous, rating it “2, 2 to 3.” Like Orville and Alan, he also considered his hobbies to be important sources of his life satisfaction. Like Geoff, he mentioned the importance of having a creative job as a potential booster to his life satisfaction.

The participants’ spontaneous inclusion of factors other than traditional material and interpersonal ones point to the importance of broadening investigation into life outcomes to include more subjective factors such as personal and physical domains. The inclusion of the physical domain as an important factor of life satisfaction by two of the oldest participants suggests that the importance of this domain may increase with age. It is interesting, however, that factors identified by participants coincide with factors already identified in the previously-reviewed general literature on quality of life.

9.3.3 On Pierre’s Life Experiences

9.3.3.1 On Pierre’s Realization of Being Different

Pierre realized that he was different from his peers when he was about 9 years old. This timing is close, although a bit late, to what Attwood (2006) identified in his clinical practice as typical for high-functioning autistic children—between ages six and eight—which was also documented in autistic individuals’ autobiographies (e.g., Hall, 2001; Newport, 2001; Sainsbury, 2000; Tammet, 2006).

Pierre remembered that at the beginning, he thought that “the other people were the problem,” not him, as did many other autistic individuals. For example, Clare Sainsbury (2000) wrote “I used to think that they were silly, but now I am beginning to understand that I am the one who is all wrong” (p. 8). Ten-year-old Kenneth Hall (2001) thought the same:

I always knew I was different and that I wasn’t quite like other children. It’s hard to say exactly how I knew. I detected some differences and I felt that things were not the same for me as for other children. Other children seemed to behave differently, play differently
and talk differently, but I didn’t know why. At that time, although I felt different I felt normal about being different. I thought I was the normal one and that it was the other people who were different, not me. (p. 14)

Although Pierre could not remember how he came to the realization that he was different from his peers, it seems that his insight was related to his experiences with bullying after he skipped a grade. Experiences of being bullied in school are almost universal among autistic individuals, and they will be explored in more detail in the section on Pierre’s most important life experiences.

9.3.3.1.1 Other Participants

Howard. Howard believed that he started to feel that he was different than his peers when he was in Grade 1: “Probably when I started going to speech [therapy]. I went to the speech [therapy] in Grade 1.” Asked if he could remember any specific events related to that feeling of being different, he replied, “Oh, probably being teased, I’m not sure. I don’t usually talk [about] my negative stuff [smiling].” (Several attempts to jog Howard’s memory were unsuccessful—he always replied, “I don’t remember.”)

Alan. Like Howard, Alan also believed that the first time he felt he was different from other children was when he was in Grade 1:

Well, I just was very young, at a very young age—when I was about 6, 7, when I was reluctant to . . . couldn’t speak the language in French immersion school, I couldn’t play games, I couldn’t . . . couldn’t make any friends at all, those things.

Asked how he felt then, he replied, “I felt withdrawn, that I didn’t fit in.”

Mike. Like Alan, Mike also felt that he was different from other children when he was very young. In fact, he said, “I’ve always known there’s a problem, but I was trying to find an answer.” Indeed, Mike remembered many experiences that contributed to this realization. When he was six, he was referred to a psychiatric examination because he could not adjust to a group environment. He then “missed a year of schooling” because he was so different that the school board did not know how to educate him. The school that did accept him soon expelled him. After
that, he went to a special school, in another town, where he was educated in a one-on-one setting. While in that school, he said, “I used to sit by myself. We called it the dungeon, and that’s where we ate our lunch, but I sat by myself.” At recess, and on his way home, he was bullied. All these experience made Mike feel that the world was “very scary” and that he, like Alan, “didn’t fit” in it.

**Orville.** Like Mike, Orville also placed the beginning of his feeling of differentness from his peers in Grade 1. He said that the main contributor to this feeling were his experiences of being bullied. He also said that he was bullied since the beginning of his schooling and that these experiences made him feel isolated, and different, from other children:

> The first clues came before and after the scheduled classroom times and during recess, when other peers would tease me with questions such as “Who do you think you are, smart Alec?” and other taunts that got progressively more into foul language over the years.²²

Orville also believed that his teachers made a significant contribution to his feeling of differentness by attempting to make him “fit in”: “They pressured me to do things according to the way they wanted them to be done” whereas he needed to do things his way: “I was leaning towards creativity.” Moreover, he said that after the first grade most of the teachers treated him the same way other students did. Orville also said that “as the taunts (from other peers) increased to daily routines on the part of these peers, and the teacher (the same in Grades Four and Five) became very upset, at times, with me,” his realization of his difference from his peers became more and more clear. He estimated that he was fully aware of the difference when he was in Grade 4 (i.e., 10 years old).

Like Pierre, Orville also believed that his difference from others, to which he referred to as “my persistence at questioning everything”—including the rules for baseball and soccer—was a good thing. He saw his difference as one between his “leaning towards creativity” and others’—both his peers and his teachers’—as wanting to maintain a *status quo.*

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²² Orville’s quotes in this section were taken from a follow-up email.
**Jimmy.** Jimmy also remembered feeling different early in his life, when he was approximately between 5 and 7, but not having a full awareness of this difference until he was in his early 20s. He said, “When I was younger, I had that feeling—it was more of a general . . . kind of back of my mind thing.” Asked if he could remember any specific events related to that feeling, he replied, “I don’t have any real specific memories, but I do remember . . . I do remember thinking as a kid . . . just feeling different.” This feeling stayed with Jimmy throughout his schooling, “until I got out of high school and started thinking that, maybe, I was mentally ill.” When asked what made him think that he was mentally ill, he replied,

> Just all the, you know, all the fear, and the insecurities, and phobias, and anxiety—all the time, and just, you know, being afraid of people, and just the fact that it wasn’t something I grew out of. I wasn’t growing out of it. It wasn’t going away. And so, I mean, I recognized that I had a lot of the symptoms of depression, so I just started to, sort of, pursue that as, maybe, that’s what’s wrong with me.

**Geoff.** Like other participants, Geoff also felt that he was different from other children when he was very young, but he did not “truly realize” that until he was in Grade 7. He said, “I guess, I knew that I was quiet, and as a young boy I was studious.” He also said, “I took school very seriously, and I was good at it, and it was important to me.” He added,

> Looking back on it, there were signs of difference from very early on, but I don’t think I recognized them. I don’t think I had any thought that I was different, or I wasn’t really thinking about what anyone was like. So I think the first time I really truly realized it would have been in Grade 7.

Like Pierre, Geoff fully realized that he was different in some negative sense after his experiences of being bullied. He said, “I was being bullied, that was to me the first real clue.” He remembered the following incident:

> One day early on in Grade 7, this guy came up and I was, you know . . . I was a bit geeky, and I was dressed funny and all that, so I was obviously a target—though I didn’t know at the time—for being bullied, you know. And this guy came up to me and asked me if I was gay, and, being a good Asperger kid, I thought of the dictionary definition of gay, meaning happy and carefree, and I said, well, “Yes, I am,” you know. And I didn’t think much of it, you know. And he was all like, “Oh, I thought so.” And then the next day, you know, there were all these, you know, kids, like, laughing at me, and I didn’t understand, you know, but I think I realized then, Well, there’s something going on here because . . . not everybody is being treated the way I’m being treated, and I don’t understand.
At that time, Geoff said, “I learned how socially awkward I was. I think it was kinda hidden before that, or it wasn’t really an issue.” He said that among the first things he noticed as being different about him was his way of dressing: “I was dressing differently. I didn’t really care how I dressed.” However, he said that “instead of saying, What’s wrong with me? I was saying, What’s wrong with them?” Nevertheless, after many repeated incidents of bullying, which led Geoff to change schools, and after another particular incident involving an open rejection by a girl, to which Geoff referred to as the turning point, he started to feel differently and to see “different” in a negative sense:

I can think of one thing very clearly. I switched schools [pause] . . . because I was really getting bullied, I switched schools two months into Grade 8. And I was fine at the new school for little while, and then, there was end-of-year dance, and I went to it, and I, you know, I wrote this girl a note asking her to dance with me and gave to her friend to gave it to her, or something. And this is all written down, of course, and the girl said through her friend, I believe, you know, “Well, she wouldn’t dance with you if you were the last guy on Earth,” and I was so devastated, and I walked out of there, and I cried, and right there, I made a decision that this was just too painful, and I wasn’t going to do this anymore. And I was just going to cut this part of my life away entirely, and I was going to just go to school, and do my homework, and nothing else. So that was a very dramatic, sort of, moment of decision. And it precipitated, you know, an emotional shut-down that lasted all through high school.

These experiences had a negative effect on how Geoff felt about himself. As he put it, “I was starting to feel bad about myself.” He also said,

What was happening—I think, more on a subconscious level—was that it was really seriously affecting my self-esteem and that I came out of it feeling I’m no good. I’m no good. And I wasn’t really asking, Why do I feel this way? I wasn’t that self-aware yet.

Perhaps one of the reasons why Geoff did not ask why could be found in his emotional state at the time: “What I felt about myself was nothing. I didn’t feel anything about anything. I was shut down.” Indeed, it took Geoff much longer before he was able to actually see how he was different from others and start feeling better about himself, as well as about others. Interestingly, he said that writing about his experiences helped him put the pieces together:
Honestly, I think I really only truly pieced it together when I wrote that section of the story in the book [his autobiography]. [...] And that helped me, sort of, forgive them and feel, you know, feel better about it.

9.3.3.1.2 Interpretive Summary

Like Pierre, the other participants in this study felt different from their peers from very early in their lives. Unlike Pierre, who identified Grade 3 as when he first realized that he was different from other children, almost all other participants placed the initial realization at the very onset of their schooling—Grade 1. However, several participants also described how a full translation of their initial vague feelings of being different into a conscious realization was a very gradual process that took many years. For example, Jimmy said that he was only fully aware of being different in his 20s whereas Geoff needed more than 30 years to put all the pieces together. Geoff’s account is a particularly good illustration of how complex the process of this realization could be, and how that process both influences and depends on emotional processes.

Autobiographical literature also contains descriptions of the long self-understanding process. For example, Temple Grandin (1995c) made a reference to a TV show that she watched while she was in college, which “helped me finally understand how I was different” (p. 131). However, for many individuals, including Geoff, it is only after they get diagnosed with autism that the pieces start being put together (which I discuss next).

Like Pierre, three other participants (Geoff, Howard, and Orville) also explicitly identified experiences of being bullied as the “first real clue” that they were different from others. (I discuss these experiences in more detail in one of the later sections.) Other contributing factors to the realization of being different included a feeling of not fitting in (mentioned by Mike and Alan) and not being able to make friends (mentioned by Alan and Sarah).

Like Pierre, two other participants (Geoff and Orville) also said that they, at least at the beginning, saw the difference as a problem of the others. However, other participants suggested that they always knew that it was themselves who were the problem. These opposing ways of making meaning of the observed differences are also found in the autobiographical literature of autistic individuals. For example, as already mentioned, Kenneth Hall (2001) and Clare
Sainsbury (2000) believed, at least at the beginning, that others were “wrong” whereas Sean Baron (Barron & Barron, 1992) thought the opposite:

I had known I was different from other kids for a while because I watched others in the neighborhood. Now, in school, I tried very hard to be “normal” and act like them so that I didn’t stand out. I did not want to be different because I knew that different was wrong. (p. 83)

9.3.3.2 On Pierre’s Getting the Diagnosis

Pierre was diagnosed with autism as an adult—when he was 39 years old. His diagnosis was a result of his search for psychiatric help because of his feeling unhappy with his life during the transition from school to work. This path to diagnosis is fairly common among autistic individuals. Like Pierre, many high-functioning autistic individuals obtained their diagnosis during a visit to a mental health professional regarding their depression or anxiety—not regarding their social difficulties (e.g., C. Mitchell, 2005; see also Attwood, 1998, 2006; Barnard et al., 2001; Tantam, 1991; Wing, 1981). Moreover, according to Tantam (2000b), difficulties with adaptation to new social challenges, such as leaving school and finding employment are typical triggers that lead to an Asperger syndrome diagnosis. As Temple Grandin observed in an earlier quotation, high-functioning autistic individuals could thrive in academia but are quite unprepared for the transition from school to work (1995c).

Given Pierre’s account of persistent bullying, his intense reaction to it, and his parents’ and school personnel’s knowledge of them, one might find it surprising that Pierre’s socializing problems did not sound an alarm for a psychological assessment, which in turn could have facilitated an earlier diagnosis. However, in light of the literature on Asperger syndrome, this does not appear to be an unusual occurrence: in a total population study, Gillberg and his colleagues (1998) found that about half of Asperger syndrome cases were not referred to either doctors or psychologists during schooling—even when teachers noticed the problems. Similarly, in a large parental survey, Barnard and colleagues (2001) found that almost half (i.e., 46%) of individuals diagnosed with Asperger syndrome received the diagnosis after they reached 17 years. Clinical, case, and other empirical accounts also corroborate these findings (Attwood, 2006; Bashe & Kirby 2001; Engström et al., 2003; Gillberg, 2002; Hurlbutt
& Chalmers, 2004; Ritvo, Ritvo, Freeman, & Mason-Brothers, 1994; Sperry, 1998; Tantam, 1991, 2000b) as do autobiographical ones (e.g., Gerland, 1997; Holliday Willey, 1999; Lawson, 2006; Meyer, 2001; C. Mitchell, 2005; Newport, 2001; Prince-Hughes, 2002, 2004; Schwarz, 2004; Spicer, 1998a). Two recent anthologies of life experiences of autistic adults provide good illustration of this issue. In the first (Prince-Hughes, 2002), only 1 out of 12 contributors was diagnosed during childhood, while in the second (Edmonds & Beardon, 2008), all 12 were diagnosed as adults.

The fact that Pierre (and so many other autistic individuals) was never referred to a mental health professional for an assessment by his teachers during his school years, and a lack of suspicion from his parents, becomes less puzzling—but not completely—when we consider a comment by a fellow autistic person, Mark Romoser (2000), who said, “I was doing too well in school to possibly be autistic!” (p. 246). This may suggest that autistic people who, like Pierre, do well academically, perhaps, do not receive enough attention because the school is overly (if not only) concerned with intellectual, and to some extent physical, development but not with “whole people”; that is, with people who develop emotionally and socially at the same time (Case, 1988).

9.3.3.2.1 Other participants

Mike. As already mentioned in the introductory description of Mike, although even kindergarten staff noticed that he “didn’t fit in” and referred him (at age 6) for psychiatric assessment at a renowned pediatric hospital in 1970, and despite the psychiatrist’s observations of Mike’s social differences, Mike only received a diagnosis of learning disability. Three decades later, in his work environment, Mike’s social idiosyncrasies were interpreted as delusions, and it was only after Mike’s own research into his problems that he was finally diagnosed as autistic at age 45, after a 38 years delay. It is interesting that during his extensive Internet research, Mike was able to find ample information about autism including several self-assessment questionnaires, whose results confirmed his initial hunches. (It is also important to note that Mike’s initial diagnosis of learning disability did not lead to any special treatment of his social difficulties. Instead, the
school’s way of dealing with them was to either expel Mike from school or to isolate him from others.)

**Orville.** Orville started undertaking psychiatric and neurological assessment when he was 12 years old. However, at that time (1957) only Kanner’s type of autism was recognized. Orville’s several later assessments also occurred before 1994, and it was not until 1995, one year after the publication of *DSM-IV*, that he was finally diagnosed with Asperger’s Disorder at age 50, thirty-eight years after his initial referral for a psychiatric assessment and after at least as many years of his, his parents’, and his teachers’ “wondering” about his problems as well as their active search for answers. As Orville put it, “I’ve been through so many psychiatrists, psychologists, social workers over the years, but nobody could provide me an answer.” It is interesting that Orville was formally diagnosed after he, like Mike, first diagnosed himself based on his own research into his problems, which was prompted by someone’s asking him about the *Rainman* film.

**Geoff.** Like Pierre, but unlike Mike and Orville, Geoff was never referred by school staff for an assessment. However, in his twenties, he started looking for professional help in his effort to deal with depression and anxiety, but his encounters with mental health professionals did not lead to a diagnosis of autism until his chance discovery that he might be autistic. Here is his description of that discovery:

> I was on an e-mail list for people who consider themselves involuntary celibate, which means they want to be in relationships but they’re blocked. So I was on this email list, and this guy one day posted something about . . . he misspelled it, he spelled it “Ausburger syndrome,” or something, and I’ve never heard of it, but he posted something about it, and he said, you know, these people are kinda nerdy and they like to read maps, and I’ve always loved reading maps, so that struck me right away. Oh, what’s this? I thought I should look into this. So I did some research—this was in 1998—on the Internet, and I started reading about Asperger syndrome, which I never heard of, and as I read it, I was, Oh my god, that’s me, that’s me, that’s me.

Several years later, in 2002, when he was 40 years old, Geoff was formally diagnosed with “residual type of *Asperger’s Disorder.*” As noted in the introductory description on Geoff, the psychiatric report included a list of symptoms Geoff identified himself prior to being diagnosed; however, perhaps based on his relatively good social adjustment at the time (Geoff was working then), Geoff received a diagnosis reserved for those who do not meet the full criteria for a...
disorder, which require “clinically significant impairment in social, occupational, or other important areas of functioning (Criterion C)” (APA, 2000, p. 80).

**Jimmy.** Like Pierre and Geoff, Jimmy was also never referred to an assessment during his schooling. However, like Geoff, after finishing high school, he started looking for professional help, believing that he was “mentally ill.” Although he obtained several diagnoses, including depression and social anxiety and was in frequent contact with mental health professionals after the introduction of *DSM-IV*, he was not diagnosed with autism prior to his chance Internet self-diagnosis. Jimmy was 39 years old then. He described his emotional experience of this discovery:

I was watching TV show about autistic kids, and one of the kids . . . I just felt like I knew, I understood how he was thinking, and how he was feeling. I do that a lot, I mean, I am always trying to find things, behaviors in people, in movies, in TV, that I can identify with to try and, sort of, help me figure it out [tongue click]—I’ve done that a lot. And this was just another one of those . . . for I was like, “Yeah, I get that . . . that kid, I know, I understand where he is coming from.” And so I just decided to go online and look . . . look up adults with autism and just see what was in there. And as soon as I . . . as soon as I found the Aspergers, I just . . . I knew, right away. I started crying.

When asked why he cried, he replied,

I don’t know. I guess, you know, it was an answer. It was . . . a lot of things that I never even thought about as symptoms of anything—just . . . they are just part of what I am—were . . . it was all in there, so many things.

Asked to say more about his discovery, he said, “Just, you know, the way I think, and, [sighs] you know, all of the social things, and, yeah, all of it. [. . .] Well, I wrote it down . . . actually.” In fact, like Mike, and Geoff, Jimmy also did extensive Internet research including making notes about all of the characteristics that applied to him:

I went to a few different sites and started doing some research [tongue click] and looking things up and made a lot of notes—wrote down about three pages worth—and just gave it to [. . .] my shrink. [. . .] He agreed.
*Alan.* Like all other participants presented so far, Alan was also diagnosed in his adulthood, when he was 20 years old. Although he was assessed by mental health professionals many times since childhood, like Orville, he never obtained any definitive diagnosis earlier.

*Sarah and Howard.* Sarah and Howard were diagnosed in their teens—when they were 12 and 15 years old, respectively. However, it is important to note that Sarah’s psychiatric report includes a note about her parent’s numerous visits to developmental pediatricians who always assured them that “there was nothing wrong with Sarah."

### 9.3.3.2.2 Interpretive Summary

Like Pierre, most other participants in this study were also diagnosed in their adulthood. In fact, only Howard and Sarah were diagnosed in adolescence—when they were 12 and 15 years old, respectively. Of the participants who were diagnosed in adulthood, only Alan was diagnosed in his early adulthood, when he was 20, whereas all other participants were diagnosed in their mid-lives: like Pierre, Jimmy, was also diagnosed when he was 39; Geoff, when he was 40; Mike, at 45; and Orville, when he was 50. This pattern is consistent with literature on high-functioning autism (e.g., Attwood, 2006; Gillberg, 1998). Although Sarah and Howard were diagnosed at much earlier ages than other participants, based on their symptoms, which included difficulties with forming peer relationships, self-talk, establishing eye contact, and motor mannerisms, it is still surprising that they were not diagnosed earlier.

The participants’ experiences with obtaining high-functioning autism diagnoses demonstrate what could often be a decades-long wait: Orville and Mike received diagnosis of *Asperger’s Disorder* at 48 and 38 years, respectively, after initial referrals for psychiatric assessments, whereas Geoff and Jimmy spent about two decades visiting mental health professionals before being diagnosed with autism. Long waits for diagnosis are also commonly found in autistic individuals’ autobiographies (e.g., Lawson, 2000; Mór, 2007; Schneider, 1999; see also Attwood, 2006; Punshon, Skirrow, & Murphy, 2009). However, it should be noted that before the publication of *DSM-IV* in 1994, even when autistic children were referred for an assessment
at an early age, they would rarely receive the diagnosis of autism if they had normal or near normal language and intellectual abilities, which Mike and Orville’s life histories illustrate well.

Unlike other participants, Pierre appears to be the only participants who received a diagnosis of high-functioning autism on his first attempt. Other participants either received some other diagnoses such as Learning Disability (Howard; Mike); Developmental Dyslexia (Mike), Delusional Disorder (Mike), Social Anxiety (Jimmy), and Depression (Jimmy) or no diagnosis (Orville and Geoff), whereas Sarah waited several years before even getting a referral for a psychiatric assessment. This pattern is also often mentioned in the autobiographies of high-functioning autistic individuals (e.g., Lawson, 2000; Schneider, 1999; Williams, 1992; see also Attwood, 2006).

Except Pierre, all other participants diagnosed in adulthood first either self-diagnosed (Mike, Orville, Geoff, and Jimmy) or their parents had a suspicion about autism before obtaining a formal diagnosis (Alan). This pattern is also consistent with high-functioning autism literature (Attwood, 2006). It is also consistent with having high motivation for understanding oneself and, in case of Alan, with high parental motivation in understanding their autistic children.

Finally, it is interesting that several participants mentioned that chance learning about autism led them first to believe that they might be autistic and then to be diagnosed with high-functioning autism. This was the case with Orville, who first heard about autism when somebody asked him about the Rainman film, Geoff, who first heard about Asperger syndrome in an Internet discussion forum, and Jimmy, who first heard about autism through a TV show. Their reactions to their discoveries were also similar, resembling an “aha!” experience described in problem-solving literature.

9.3.3.3 On Pierre’s Reaction to Getting the Diagnosis

Pierre’s reaction to his diagnosis of Asperger’s Disorder was mixed. He said that although the diagnosis provided him with “a new category of people to be in” as well as “the chance to look at [him]self in a new way,” both of which he liked, he was somewhat skeptical about “really”
belonging to the category of autistic people. From his perspective, it was too neat of an idea to explain a person with reference to only one category of people. He also said that he did not believe that he was “that” different, perhaps suggesting some discomfort with being diagnosed with a psychiatric condition.

Pierre’s reaction to getting a diagnosis is only partially typical of other individuals diagnosed with Asperger syndrome in adulthood. Like Pierre, many autistic individuals found it to be, mostly or predominantly, a good thing. However, unlike Pierre, many, although not all, autistic individuals diagnosed in adulthood referred to the diagnosis as a relief (e.g., Dumortier, 2004; Gerland, 1997; Jackson, 2002; Lawson, 2006; Newport, 2001; see also Attwood, 1998, 2006; Barnard et al., 2001; Bashe & Kirby 2001; Huws & Jones, 2008; D. Murray, 2006; Punshon et al., 2009). However, like Pierre, others also experienced some discomfort associated with being diagnosed with autism (see, for example, Attwood, 2006; Huws & Jones, 2008). As Gunilla Gerland (1997) expressed it, the diagnosis was “a relief, but at the same time a pain” (p. 238). Similar pain might have contributed to Pierre’s denial of being “that” different. Gunilla described her reaction to reading her diagnosis as follows:

But when I read the letter, it saddened me. It began with the words, “Gunilla Gerland is a woman with high-functioning autism…” I wasn’t that! I hadn’t agreed to be called that! The letter couldn’t be about me. I couldn’t see myself in those words—”high-functioning autism.” It wasn’t something I could say about myself. Gunilla Gerland simply didn’t fit with the words “high-functioning autism.” They couldn’t be put in the same sentence. (p. 239)

It is interesting that although Pierre said that he liked “the chance to look at [him]self in a new way” that the diagnosis provided, he did not spend much time trying to learn about autism and trying to figure out whether any of the available information might be relevant for his self-understanding. He said, he “wasn’t in a hurry to read about it,” but everything else he said in the interview and wrote in his diaries is more consistent with actually avoiding learning about it than with leaving it for another time. For example, in light of the fact that Pierre is a voracious reader (as he said, he reads anything, which his diaries corroborate), not reading any books about autism (if we exclude the novel with an autistic character) is surprising. However, avoiding seeking information about one’s diagnosis has also been documented (albeit rarely) in literature on
autism. For example, in a recent qualitative study, Huws and Jones (2008) reported about two autistic adults who actively avoided information associated with autism:

David: I don’t really like to think about what I struggle with because it puts us down too much [. . .] I’d rather just be helped without knowing because life can put us down when we think [. . .] Well I’ve heard of programs [on TV] and stuff, but I wouldn’t really watch it so you know, because I wouldn’t feel comfortable.

Clare: I haven’t read the book on autism which is in the library. I don’t really want to read about my autism. (p. 104)

This avoidance of knowing is often interpreted as a coping strategy. For example, Pinder (1990) found that people differ with regard to seeking information about health issues, which led her to propose the following categories of people: seekers (those who actively search for information and new knowledge relevant to their health), avoiders (those who prefer not to know rather than to confront fear associated with knowing), and weavers (those who make some effort to obtain information but are very selective about what they attend to). From this perspective, which Huws and Jones (2008) found to be applicable to autistic adults, Pierre could be described as a weaver: he looked on the Internet—somewhat superficially—and after finding some information about Geek syndrome that he could identify with, he stopped researching further.

In contrast to Pierre’s approach to learning about autism, almost all high-functioning autistic individuals who published their autobiographies eagerly sought information about autism, and not only after they received the diagnosis (e.g., Grandin, 1995c; L. Jackson, 2002) but also, as already mentioned, before it, which, in many cases, led to self-diagnoses before formal ones (e.g., Garland, 1997; Holliday Willey, 1999; Newport, 2001; Prince-Hughes, 2002; Sainsbury, 2000; D. Williams, 1992). The autism-related information-seeking behavior of autistic individuals is also documented in clinical and case accounts, all of which suggest that, starting from adolescence, autistic individuals read avidly about autism, have extensive knowledge about it, and often self-diagnose themselves (Attwood, 1998, 2006; Gillberg, 1991, 2002; Hurlbutt & Chalmers, 2002).

9.3.3.3.1 Other Participants
Mike. Like Pierre’s, Mike’s feelings were mixed. Asked how he felt when he got diagnosed with Asperger syndrome, he replied, “I didn’t feel the greatest, but in one way, I feel that it’s sort of . . . to me personally . . . it gives me [pause] some relief, personally—that I have an answer.” He later added, “It’s made me feel better,” and “it’s sort of gives me a confirmation to being different. I never really understood why. I didn’t have a name for it. I just knew that I was different.” Mike also said that the diagnosis of Asperger’s Disorder makes him feel better because it fits his problems much better than the Delusional Disorder diagnosis he previously received.

Geoff. Like Pierre and Mike’s reactions, Geoff’s reaction to his diagnosis was also mixed. Like Mike, he felt relief; however, he was also confused with the specific diagnosis he received, residual autism, which did not provide him with a full answer as to where “exactly” he fits:

I think I felt relieved. I think I’m still a little bit confused because, [long pause] well, he diagnosed me with . . . “Residual Asperger syndrome” is what the diagnosis is. “Residual,” meaning left over from childhood, and I can see that, you know, I am not like I was a kid, but there’s still some part of it left over, you know, and so I’m still trying to figure out where I exactly fit into it because sometimes people meet me, and they talk to me, and I tell them a little bit about it, and they just shake their heads and say, “No, you’re not,” you know. So I get that a lot, “No, no you’re not.” Well, yes, I am, but . . . So it’s, kind of . . . yeah, it’s a little confusing.

Jimmy. Like Mike and Geoff, Jimmy was also relieved when he got his Asperger’s Disorder diagnosis, but unlike them, he did not have any negative feelings about it. Like Mike, Jimmy said that he was “relieved” because the diagnosis helped him understand himself better and because it answered many questions that his previous diagnoses, Social Anxiety and Depression, left unanswered. He said, “It’s an answer. [ . . . ] Why am I like this, kind of a thing. [. . .] “[It] really changed my whole way of thinking about myself.” In a follow-up e-mail, he explained:

After the diagnosis I was able to think of myself as someone who is “wired” differently than most people. I think in a different way, and I was born that way. As opposed to thinking of myself as inferior or inadequate. Before the diagnosis I always felt like there was something I was missing—something that I’m not doing right.

Orville. For Orville, the diagnosis was also a big relief; like Mike and Jimmy, he was searching for an understanding of his differentness from others his whole life. As for Mike, the diagnosis
was a confirmation of his “intuition” that he had a “chronic social learning disability” and that his lack of relationships was not a matter of his lack of effort. He described his reaction to the diagnosis as follows:

Well, I felt, at first, a sense of relief is the word I think of. At least confirming that what I’d been thinking all along that there had to be a basic issue, I call it problem, underlying difficulty, and that, with the social . . . like I said, chronic social learning disability I described before. And this would [be] just confirming what I’d been saying all along. It was a confirmation of that in that it wasn’t just [as] people like the social worker and others who were telling me for that, “Oh, it’s all in your mind. If you think positive, and you go out and you make up your mind to meet people and get to know them well, you will be able to do it,” and everything like that, “Now think positive, and now get out there and meet people,” and that. I knew it had to be deeper than that, and this diagnosis was a confirmation of that—that’s what I felt at the time—that indeed, it was more complex than what these other people were trying to imply it was.

For Orville the diagnosis was also important because it gave him new ways to describe himself not only to himself, but also to others:

I was glad to find out that at least I could begin to relate to others in the sense that, not so much that I was alone before that I was part of it, not knowing condition, but also being able to describe it to other people as well, whereas before that, I had no terms to use for describing my feelings or social problems other than people trying to, I say, point their finger back at me and saying, “Well, it’s all in your mind” type of thing. [chuckles]

Indeed, getting the diagnosis was so important for Orville that he considered it one of the most significant experiences of his life. He explained why:

[The diagnosis] was the answer to this search that had been going on for many years because [I’ve] been to so many other professionals over the years, right from the earliest years right up and [I] couldn’t get an answer, and my parents couldn’t get an answer, and through adulthood the same thing. And I was told that because they didn’t have answer as though it was just to me to fix my behavior. But finally the relief came, again, in that it wasn’t just up to me to snap out of it, as the saying goes, but there was a legitimate medical concern there that I tried to express up till then, but nobody seemed to want to believe me. And now it was a confirmation of what I’ve been feeling all these years, almost a form of intuition I’d say that there had to be something else like this, I described before, this “chronic social learning disability” I had to call it before I got diagnosis, and that was confirmation. And again, it was, I’d say, very positive experience, again, this relief in though just a couple of years before that I’d been to the [King’s] Hospital, to all these other professionals, and they couldn’t come up with an answer, and yet it was the help of people who’d seen the movie Rainman that actually brought this about and brought on the diagnosis, and that was again a kind of a surprise the way it worked out
that way. And then by getting that diagnosis, like I explained before, I was brought into contact with quite a few other people around, and then I was able to get on the Internet—which was just coming into expansion at the time in ’95, and groups were starting to form—and meet people, and [it] just grew from there that I belong to quite a few groups, and I run two groups myself on the Internet that have close to about 400 members in each group.

Likewise, Orville considered his decision to “to search for an answer” about his problems the most important decision he ever made. Although his description of his search for a diagnosis was already quoted in the discussion about his persistence, I repeat it here for the sake of completeness of his account related to the diagnosis:

[I] search[ed] for an answer as to why I was having this problem with social bonding over the years and reading as much as I could about it, even after going to [Montréal], searching for answers there and even though I couldn’t find answers the first couple years, it didn’t stop me. I kept discussing it even with friends and people that I met at the college, and that, and finally being . . . getting these hints of an answer, pursuing it up until finding the person that was willing to give me the diagnosis.

Orville also said,

[I] was convinced after reading all these books that it had to be something deeper than just behavior. [It] wasn’t a matter of me just learning all these behavior techniques that were available in these books and trying to practice them because I even tried that, but even that didn’t even change anything in my life, so I felt there had to be something deeper, [it] had to be a medical condition that even, as I said, [I] didn’t have a name at the time—that’s when I had to come up with that name I used—that it had to be deeper than just me smiling at people or trying to show interest in them or something else like that, that you can’t just smile and all of a sudden you’ve become friends with everybody, [chuckles] type of approach, the way other people were saying.

Orville believed that if he did not make that decision, I would just been . . . just . . . resigned is the only word . . . not having any friends, and that would be it, and just living alone all the time, and not even knowing anything about autism or Aspergers or anything like [I know] today, just staying by myself all the time, and hardly [have] any contact if I didn’t search for answers.

Asked how his life would have been different were he not diagnosed with Asperger’s Disorder, he replied that he would have still been searching for answers and that he would have been frustrated not knowing why he was different:
I think [I] still would be [involved in] that search . . . that mystery, as though there’s gotta be something to it other than people just telling me the usual stuff years ago, “Oh, come on, if anybody else can do it, you can do it. You can make friends, you could go and play soccer with those other kids in the field, you can go to the party this Saturday night and join the fun of the rock ’n’ roll music and the dancing on the floor,” and all that. And I’d just be just, again . . . feel as though I was hounded by the same advice being poured down to me, almost like pouring alcohol down my throat, is what it felt like every time somebody came up with that, and that’s . . . I’d feel more and more frustrated all the time, I think, if I didn’t get this diagnosis.

Orville also said that getting the diagnosis was a significant learning experience for him because up until that moment even, I had never heard of the term Asperger syndrome at that time. I’d heard about autism only as a childhood disorder, but here I was an adult still having problems socially, and all the rest. But finally, with this statement by this diagnostician [. . .] that is when things seem to change more, I’d say, in my life than in any other one moment, there. And that’s almost like a floodgate opened and everything’s been different since then.

Sarah and Howard. The reactions of the 2 participants who were diagnosed in their teens, Sarah and Howard, were also positive. As already mentioned, the diagnosis seems to have played a particularly significant role in Sarah’s life in that it provided her with an important reference point against which she could measure her accomplishments. She said, “I feel quite happy about [the diagnosis]” because “now I know who I am, how much I’ve accomplished. I’m feeling quite proud of myself.” It is also interesting that, like Mike, Jimmy, and Orville, Sarah said that the diagnosis answered some of the questions she had about herself. As she put it, “[When] I found out about the diagnosis, I realized why I was like . . . why I am like that.” She also said, “I remember asking myself, like, why I had trouble in school, like, I wasn’t making that many friends with my classmates. [. . .] I wasn’t doing very well, with tests and stuff.” Like Sarah’s, Howard’s reaction was also positive, although he was not told about his diagnosis at the same time he received it.

Alan. Unlike all other participants, Alan’s reaction to the diagnosis was entirely negative. He said that getting the diagnosis was “not a good moment” because he could not accept it and that it worsened his violent outbursts. As he put it, “I just felt I couldn’t accept it so much and that it
just pushed me deeper [into a] hole—of hitting doors, smashing, wrecking irreplaceable things.”

He also said that the diagnosis made him feel even more different than he felt before:

> It just exacerbated my problems. [. . .] Just made me more upset because I couldn’t accept [it]. [. . .] I just felt like I’m outcasted, more like . . . [I] felt like [I] was different. [. . .] It was just like a trigger that blew up, like a bomb or something.

Alan still felt so strongly about getting the diagnosis that he chose it as one of the most significant events of his life. He said that the diagnosis made his life more difficult and believed that if he did not know about it, he “wouldn’t be so upset.”

It is interesting that Alan found reading books and watching TV shows about autism particularly helpful in dealing with the diagnosis. It is also interesting that Alan chose reading the same book Pierre mentioned—*Curios Incident of the Dog at Night Time*—as one of the most important events of his life. He said, “[Reading the book] made me feel good. It made me feel good, feel that I am trying . . . that somebody is trying to succeed and trying to [be] accepted for what they are.” He also said, “[It] made me think a little bit more about what autism is about,” as well as about “trying to fit in [. . .] and trying to be accepted.” He found it particularly helpful to read about others who had “similar qualities like I had, like, didn’t like the noise of the subway humming or subway roaring and all those things, you know.” Moreover, he said he was inspired by the book: “I understood that the boy had similar things that I was afraid of. [. . .] I felt inspired by it. I felt really good about it.”

### 9.3.3.3.2 Interpretive Summary

Like Pierre, most other participants had positive, or mostly, positive reactions to their diagnoses of autism. Like Pierre, most other participants (all except Alan and Howard) also mentioned that the diagnosis of autism contributed to *better self-understanding*, including re-interpretation of their behavior and their life experiences. However, unlike Pierre, who did not believe that the diagnosis could explain him as a person but only one of his aspects, other participants clearly saw the diagnosis as the answer to their search for an explanation for why they were so different from others. This finding is consistent with that of a recent study by Punshon and colleagues (2009), which reported that autistic adults found the diagnosis particularly helpful in providing
them with a framework for explaining their difficulties. This was also true for many other autistic individuals who wrote about their reactions to the diagnosis (e.g., Dumortier, 2004; Fleisher, 2003; Gerland, 1997; Lawson, 2000; MacDonald, 2003; McDonnell, 1993; McMullen, 2000; C. Mitchell, 2005; Robison, 2009; D. Williams, 1992). For example, Paul McDonnell (1993) wrote the following about what the diagnosis meant to him:

I always knew I was different from other kids, I just didn’t know what that difference was. For years I guessed I was retarded, mildly retarded, and that my parents were lying to me when they said that I wasn’t. That’s what kids always called me: retarded. Finally, when I heard the word autism and saw the film Rain Man, I felt that at least I had an explanation of my own life and experience. (p. 327)

Chris Mitchell (2005), who divided his life “before” and “after” the diagnosis and titled his autobiography accordingly, Glass half empty, glass half full (“Glass Half-Empty is about my life before diagnosis and Glass Half-Full is about my life after diagnosis”; p. 3), claimed that the diagnosis allowed him to not only understand himself better but also to use this new understanding in order to make informed decisions about his life. He wrote that after the diagnosis, “I felt that I was able to assess my own strengths and weaknesses rather than letting others do it for me” (p. 74). Likewise, for John Robison (2009), the diagnosis was useful not only in “helping [him] understand exactly how [his] mind differed from other minds around [him],” but also in facilitating his subsequent understanding of the sources of some of his social difficulties, which he used to improve his social skills, and his life:

For example, the simple insight that I miss nonverbal cues was life-changing. I seized upon the specific behavioral issues and set about constructing a better life. It worked. Words cannot express how much better my life is, thanks to the self-knowledge I’ve gained since learning about my Asperger’s.

Given the above-described reaction of this study’s participants, it is understandable that half of the participants (Mike, Jimmy, Geoff, and Orville; or all those who were diagnosed in adulthood) also expressed the feeling of relief after the diagnosis. As already mentioned, this feeling is also commonly reported in autobiographical writings of high-functioning autistic individuals diagnosed in adulthood (e.g., Dumortier, 2004; Gerland, 1997; Jackson, 2002; Lawson, 2006; Newport, 2001; see also Attwood, 1998; 2006; Barnard et al., 2001; Bashe & Kirby 2001; Huws & Jones, 2008; D. Murray, 2006; Punshon et al., 2009). It is also interesting to note that in
addition to the above-described reactions, Mike and Orville also experienced the diagnosis as a confirmation of their intuitions about some kind of social disability being the source of their problems.

To fully appreciate the importance of the diagnosis for participants’ self-understanding, it is important to remember that most of the participants spent a lot of time “wondering” about their differences from others and searching for answers, both from professionals and by doing their own research. Indeed, most participants made spontaneous references to both scientific and popular literature, as well as other resources. For example, participants made references to names of autism experts (e.g., Tony Attwood and Peter Szatmari), theories of autism (e.g., the theory of mind), the DSM, other well-known autistic individuals (e.g., Michelle Dawson and Liane Holliday Willey) or parents of autistic individuals (William Christopher, Jenny McCarthy, and Jim Carrey), several books about autism (*Look Me in the Eye: My Life with Asperger’s*, *Pretending to Be Normal*, *Mixed Blessings*, and already-mentioned *The Curious Incident of the Dog in the Night-Time*), one movie (*Rainman*), several TV shows, as well as numerous Internet resources. The Internet seemed to be the main source of information about autism for all participants. However, although several participants expressed their interest in learning about autism as part of their search for the right diagnosis (Mike and Jimmy read because they were dissatisfied with their previous diagnoses, whereas Geoff and Orville, who did not have any previous diagnoses, read because they were looking for answers about their subjectively felt differences from others), Alan read in an attempt to ease his acceptance of the autism diagnosis.

From this perspective, it is understandable that 2 participants, Orville and Alan, chose getting the diagnosis among the most significant experiences of their lives. However, they made these choices for opposing reasons. For Orville, the diagnosis was one of the best things that happened to him: it was “the answer” to his life-long search for better understanding of his social difficulties. He felt that if he did not get the diagnosis, he would be still searching for answers and that he would be more and more frustrated. On the other hand, Alan described getting the diagnosis as one of the worst moments of his life. It made him feel worse, even more different (an “outcast”), and he spent years trying to accept it. In fact, he still has not come to terms with it. One way to explain these contradictory experiences is to consider the context in which these 2 participants obtained their diagnoses. For Orville, the diagnosis was exactly what he was
searching for his whole life—the answer to why he was different. On the other hand, for Alan, who was perhaps searching for a way to lessen his everyday difficulties with anxiety and obsessions, the diagnosis was an additional thing to get anxious about. Clearly, the diagnosis was not helpful for what he needed at the time he received it.

It is interesting that in addition to Alan, Pierre was the only other participant in this study who expressed some difficulty with accepting the diagnosis. However, whereas Alan’s reaction was more emotional (he expressed his deep feeling of hurt and anger at getting the diagnosis), Pierre provided intellectual reasons for his nonacceptance (he found it a theoretical impossibility for one label to explain a whole person). Although several other autistic individuals also expressed their difficulties associated with accepting the diagnosis (e.g., Edmonds & Beardon, 2008; Sainsbury, 2000; see also Attwood, 2006), as well as their accompanying negative feelings, such as loss and anger (Attwood, 2004; Lawson, 2006; Punshon et al., 2009), these reactions appear to be much less frequent than those of a sense of increased self-understanding and relief, particularly if the diagnosis is obtained in adulthood.

It is also interesting that in addition to the benefits of the diagnosis for self-understanding, Orville also mentioned several other positive aspects of receiving the diagnosis. For example, the diagnosis helped him describe and explain himself to others. He found the diagnosis particularly beneficial in dealing with criticism, blame, and others’ suggestions that his social difficulties were the results of his lack of effort whereas he knew that there was more to his problems than that. Other autistic autobiographers also expressed a similar feeling (e.g., Dumortier, 2004; see also Punshon et al., 2009). For example, Dominique Dumortier remarked, “My diagnosis means I feel acquitted, personally” (p. 17). Likewise, autistic participants in the study by Punshon and colleagues felt that the diagnosis “exonerated them from being blamed” (p. 277) for their difficulties. Finally, Orville also found the diagnosis beneficial in that it opened a door for him to meet other such people with similar problems, which provided him with a sense of belonging (which was also mentioned by participants in Punshon et al.’s study).

9.3.3.4 On Pierre’s Most Significant Life Experiences
Pierre identified the following life experiences as the most significant for him becoming the person he is now: (b) being bullied and the related feelings of not being understood and supported; (c) living away from his parents’ home; and (d) connecting to the Internet. I discuss these experiences in turn.

### 9.3.3.4.1 Being Bullied

Pierre identified his experiences of being bullied and not being understood and supported by his parents and teachers as his most important life experiences. Although he first mentioned experiences of being bullied by his peers in connection with his realization of being different from his peers, this does not appear to be the main reason behind these experiences being so important to him—it is his parents and teachers’ reactions, or the “appropriate” lack thereof, that gave them such status. According to Pierre, his parents did not take his side when he asked them to, and they did not support him when he needed their support the most. As for his teachers, not only did they not understand or support him—they instead blamed him (as Pierre put it, “blamed the victim”)—but even worse, they participated in the bullying. Importantly, Pierre chose his negative experiences with his teachers in correspondence courses and the lack of support from his parents regarding his interpersonal problems as both his unhappiest and most disappointing experience. Moreover, he identified skipping a grade of school as a turning point in his life after which he felt his life was different in that he could not cope with life as well as he did before.

In the psychological literature, peer bullying is defined as repeated negative actions against an individual that occur over time (Olweus, 1993). These actions could be verbal (e.g., teasing and threatening), physical (e.g., hitting and kicking), relational (e.g., social exclusion), or indirect (e.g., gossiping; Hawker & Boulton, 2000). Peer bullying of high-functioning autistic children is well documented in clinical literature (e.g., Asperger, 1944/1991; Attwood, 2006; Bemporad, 1979; Bosch, 1962/1970; Gillberg, 2002; Hippler & Klicpera, 2003; Ritvo et al., 1994; Tantam, 1991, 2000a, 2000b; Volkmar, Klin, Schultz, Rubin, & Bronen, 2000; Wing, 1981). For example, in their review of life histories of 14 high-functioning autistic adults, Ritvo and colleagues (1994) found that they were all bullied in school. Asperger himself (1944/1991) made the following observation,
In the playground or on the way to school one can often see an autistic child at the centre of a jeering horde of little urchins. The child himself may be hitting out in blind fury or crying helplessly. In either case he is defenceless. (p. 79)

Clare Sainsbury (2000), from both her own and the experiences of other autistic individuals whom she interviewed, wrote, “Bullying and teasing were almost invariably part of the school experience of children with Asperger’s, with many people reporting being ‘teased constantly’” (p. 72). People she interviewed vividly remembered many incidents of “terrifying” (p. 72) and traumatic incidents. Therese Jolliffe (Jolliffe et al., 1992) summarized her schooling experience, which included being “kicked, hit, pushed over and made fun of by the other children” as follows:

I hated school. Parents of autistic children should never think about sending their children to ordinary schools, because the suffering will far outweigh any of the benefits achieved. The children just cannot tell anybody they are suffering . . . Although ordinary schooling enabled me to . . . obtain a [PhD] degree, it was not worth all the misery I suffered. (p. 13)

In fact, almost all autistic individuals who published their autobiographies wrote about their experiences of being bullied (e.g., Boswell, 2008; Dakin, 2005; Dubin, 2007; Fleisher, 2003; Gerland, 1997; Grandin & Scariano, 1986; Hadcroft, 2005; L. Jackson, 2002; N. Jackson, 2002; Lawson, 2000, 2003; Lissner, 1992; C. Mitchell, 2005; Peers, 2003; Prince-Hughes, 2004; Purkis, 2006; Shore, 2001; Tammet, 2006; Vincelette, 2000; Ward & Alar, 2000; D. Williams, 1992; for rare exceptions, see Holliday Willey, 1999; Newport, 2001).

It is interesting that despite an abundance of clinical and autobiographical evidence, peer bullying of autistic children received surprisingly little systematic research attention: Two studies reported (among “other” findings) that bullying is a part of many autistic children and adolescents’ lives (Green, Gilchrist, Burton & Cox, 2000; Konstantareas, 2005). In fact, Konstantareas reported that all participating parents of children and adolescents with Asperger syndrome (N = 22) said that their children were regularly bullied by their peers. However, the only study that specifically examined peer victimization of autistic children (Little, 2001) reported 94% prevalence rate based on parental reports. Yet, given that research shows that bullying victims tend not to talk about their experiences (J. S. Peterson & Ray, 2006a; Ziegler &
Pepler, 1993), which is corroborated by the first-person evidence of autistic individuals (e.g., Gerland, 1997; L. Jackson, 2002; Sainsbury, 2000), it is reasonable to believe that even this estimate is an underestimation of the true rate of peer bullying of autistic students.

Many autistic individuals reported that they did not tell their parents about bullying because they saw it as part of schooling and became used to it (e.g., Gerland, 1997; L. Jackson, 2002; Sainsbury, 2000; Shore, 2001). As 13-year-old Luke Jackson (2002) explained:

Mum used to get annoyed because she said I always left it till the bullying got too much to bear before I told her it was going on. What she doesn’t realize is that kids do this kind of thing and I was used to it. . . . There was another reason for me not telling her things too. AS [Asperger syndrome] kids don’t realize which things they are supposed to go home and tell. ‘What have you done at school today?’ wouldn’t automatically bring about the answer ‘I have been bullied’ unless that subject was specifically asked about. (p. 147)

Clare Sainsbury (2000) further elaborated,

It did not even occur to many people, myself included, to tell parents what was happening. I just didn’t think of it, which is not surprising given that at that time I hadn’t really worked out that I needed to tell people things in order for them to know them. In some ways I think I just assumed that school was supposed to be like that (my mother remembers that I would refuse to go into the school buildings in the morning and would run round and round her in little circles, but I was never able to tell her why I didn’t want to go).

It requires a certain level of social competence even to categorize what is happening as bullying. I mainly remember a painful confusion, not really knowing whether what was happening was accidental or intentional, whether this was supposed to be happening or not. Other children were baffling and frightening almost all the time; it’s only now, looking back, that I can classify some of that as bullying. (p. 74)

Although children with disabilities, both visible and hidden—as in the case of Asperger syndrome—are at higher risk of being bullied than other children (Carter & Spencer, 2006), Little (2001) found that autistic children were four times more likely to be bullied than other students. This is well reflected in the way high-functioning autistic children are usually described: as “perfect victims” (Klin, Volkmar, & Sparrow, 2000; Sainsbury, 2000; Volkmar & Klin, 2000) and “perfect” and “easy targets” (Dubin, 2007; Heinrichs, 2003) of bullies—as Asperger (1944/1991) put it, their behavior “cries out to be ridiculed”:
Autistic children are often tormented and rejected by their classmates simply because they are different and stand out from the crowd. Their conduct, manner of speech and, not least, often grotesque demeanour cries out to be ridiculed. (p. 79)

More recently, Volkmar and his colleagues suggested that it is their “social naivety” (Klin et al., 2000, p. 6), emotional insensitivity, and isolation from others (Volkmar & Klin, 2000) that make children with Asperger syndrome especially vulnerable to victimization. Indeed, research on bullying has identified two sets of risk factors for being bullied by peers, both of which are closely associated with autism: individual risk factors, such as having social and emotional difficulties, and social risk factors, such as lack of supportive friends and peer rejection (Hodges, Malone, & Perry, 1997). From her personal experience, Clare Sainsbury (2000) explained why autistic children make “perfect victims” as follows:

We have no tactics for verbal or physical self-defense, we are extraordinarily naive, we almost never tell and we can be reduced to tears of frustration and rage with delicious ease by simple ploys like making fun of our obsessions. (p. 73)

Nick Dubin (2007), also from his personal experience, suggests that anything that makes autistic children stick out—and he lists 11 such features, from lack of motor coordination to lack of knowledge about popular topics and odd (that is, advanced) use of language—invites bullying. Indeed, research has shown that “being different” not only attracts bullies, but also that “being different” includes positive characteristics such as being clever, a hard-worker, or a high-achiever (Glover, Gough, Johnson, & Cartwright, 2000; Hoover, Oliver, & Hazler, 1992). That advanced abilities can “attract” bullying is well documented in the literature on gifted students—who are also frequent targets of bullies (J. S. Peterson & Ray, 2006a, 2006b).

Keeping in mind the just-reviewed evidence, it becomes obvious how easy it was for intellectually advanced but socially and emotionally immature and friendless Pierre to become an easy target for peer bullying. (Pierre revealed in a follow-up interview that he did not have any

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23 Conversely, having friends and being liked by peers is also found to have a protective role against peer bullying (Hodges, Boivin, Vitaro, & Bukowski, 1999; Pellegrini, Bartini, & Brooks, 1999). Indeed, two autistic autobiographers who were not bullied by their peers illustrate the importance of these two factors: Liane Holliday Willey (1999) had a friend, who was popular, whereas Jerry Newport (2000) was himself popular (he had savant mathematical skills, which his peers found amusing and often asked him to perform for their entertainment). Some other autistic adults also mentioned having friends (e.g., D. Williams, 1992), however, because of their similarly low social status within the peer group, they could not have a protective function (Hodges et al., 1999).
friends during his school years.) But we must still ask why was Pierre not protected from his bullies—nor supported in any way—by his teachers. One possible explanation comes from research which indicates that teachers are generally not aware of peer bullying (Atlas & Pepler, 1998; P. K. Smith & Shu, 2000). However, this explanation is difficult to accept in Pierre’s case because he was bullied for so long that it would be impossible for none of his teachers to have known about it. Another, more plausible explanation is that his teachers simply failed to intervene. Indeed, research has found that even when teachers knew about bullying, they tended not to intervene (Atlas & Pepler, 1998; Olweus, 1993). For example, Atlas and Pepler found that teachers intervened in only 18% of the bullying episodes in the classroom. Unwillingness to intervene has been attributed to a number of factors including the individual characteristics of teachers (e.g., level of empathy), their perceptions about the seriousness of bullying, and also their beliefs regarding intervention (W. Craig, Henderson, & Murphy, 2000). Importantly, teachers often describe bullying in their classrooms as minimal and believe that it is best to ignore it (Stephenson & Smith, 1989). Moreover, when teachers do intervene, students often perceive their actions as inadequate (P. K. Smith & Shu, 2000).

Although the above-reviewed literature sheds some light on how it was possible that nobody recognized that Pierre was bullied by his peers and that he needed help, it does not help much with understanding being bullied by his teachers. Indeed, case (Bemporad, 1979) and autobiographical evidence (e.g., Gerland, 1997; O’Neill, 2000; Prince-Hughes, 2004; Sainsbury, 2000; D. Williams, 1992) have documented teachers’ bullying of autistic individuals. However, there are no studies, nor other reports, that specifically address this issue. Moreover, in contrast to the wealth of literature on peer bullying in general, there is only a small body of literature on teacher bullying. The existing literature indicates that this kind of bullying is much more prevalent than one would expect (Olweus, 1993; Rigby, 1997). In one study (D. J. James et al., 2008), 30% of students said that they were bullied by a teacher (in the specified time frame), whereas in another study (Twemlow, Fonagy, Sacco, & Brethour, 2006), 45% of the teachers admitted to bullying a student. Rigby termed this kind of bullying “educational bullying” and those who engage in it “intellectual bullies” (p. 18). He further suggested that educational bullying is “a product of intellectual arrogance” (p. 19). He wrote:
Being an intellectual bully is an occupational hazard for any teacher. The judgment is really a fine one between providing rigorous and justifiable (?) [“(?)” in original] criticism and engaging in a ruthless and insensitive exposure of the limitations of someone who is, in some respects, not your equal. . . . Wherever there is a power imbalance, whatever its source, an individual can be reduced in status, and sometimes humiliated by the insensitive bully. . . . From the victim’s viewpoint, the motive (or lack of motive) on the part of the bully is hardly the point. The consequences may be much the same. (pp. 18–19)

More recently, Rigby (2001) suggested that teachers sometimes bully because of their personal prejudice against students who are different in some way. Furthermore, teachers themselves identified a variety of reasons that range from lack of training to being burnt out to being envious of smarter students (Twemlow et al., 2006). Although not directly addressing teacher bullying, Attwood (2006) suggested that because of their social immaturity some children with Asperger Syndrome are sometimes perceived—by both their peers and teachers—as “intrusive, irritating and provocative” (p. 99) and deserving of bullying.

From this perspective, Pierre’s evaluation of his teacher’s actions as “deliberate humiliation” becomes easier to accept as reasonable. Nobody can argue that he felt humiliated, but without the above evidence, many would object that teachers could deliberately humiliate students. (It is important to note that Pierre’s characterization of “deliberate” also illustrates that autistic individuals could be sensitive to others’ intentions, challenging the theory of mind claim to the opposite; Baron-Cohen, 1995.)

Pierre also remembered feeling angry and crying after being bullied. Such feelings are also commonly reported by other autistic individuals (e.g., Andrews, 2006; Gerland, 1997; Grandin, 1995c). However, other autistic individuals also reported feeling fear and embarrassment in response to bullying (e.g., Andrews, 2006; Dubin, 2007; Fleisher, 2003; Grandin, 1995c; Hadcroft, 2004). For example, Will Hadcroft (2004), wrote about “the feeling of constant dread and fear” (p. 181), and Temple Grandin (1995c) wrote,

At puberty, fear became my main emotion. . . . Teasing from other kids was very painful and I responded with anger. I eventually learned to control my temper, but the teasing persisted, and I would sometimes cry. Just the threat of teasing made me fearful; I was afraid to walk across the parking lot because I was afraid somebody would call me a name. (p. 88)
Although Pierre never mentioned fear, his behavior (skipping school) is consistent with it. (Fear is a feeling of an anticipated threat—physical and/or psychological; Oatley & Jenkins, 1996). However, it was not clear from the interview whether he was consciously aware of it. It may also be important to note that while typically developing children usually report anger, sadness, and fear in response to bullying, autistic children usually identify anger (when bullied by peers) and sadness (when bullied by siblings), but not fear (Rieffe, Meerum Terwogt, & Kotronopoulou, 2007). And while some autistic adults were able to identify that what they felt was fear, others, including Pierre, did not.

Pierre also talked about his unsuccessful strategies for dealing with bullying. His first strategy involved physically defending himself by hitting his bullies. As described above by Asperger (1944/1991), as well as by some autistic adults who wrote about their experiences of being bullied (Gerland, 1997; Grandin & Scariano, 1986; Peers, 2003; Sainsbury, 2000, D. Williams, 1992; see also Molloy & Vasil, 2002; Tantam, 2000a), this was the preferred strategy of many other autistic, and non autistic (Glover et al., 2000), children. As Lee, an 18-year-old participant in Molloy and Vasil’s study described, “A lot of the aggression at school was retaliation against the kids picking on me. I would attempt to give them back as good as I got” (p. 33). Asperger (1944/1991) suggested that this strategy worked for some children: “In favourable cases, however, it is possible for autistic children to earn respect, even if it is mixed with ridicule, either through sheer intellectual prowess or through particularly ruthless aggression” (p. 79). This approach also worked for Gunilla Gerland (1997); however, it did not work for Pierre.

Moreover, Pierre’s parents and teachers did not approve of Pierre’s self-defensive aggression. In fact, school personnel usually do not view autistic students’ defensive reactions as attempts of self-defence and often use these behaviors as rationale for expelling these students from school (Barnard et al., 2000; Grandin & Scariano, 1986; D. Williams, 1992) or for pressuring their parents into finding other schools for their “aggressive” children (Andrews, 2006). According to Barnard and colleagues, 29% of high-functioning autistic students are excluded from school at some point—in most cases because of reactive aggression—compared with 1.2% in the total student population. As the parent of a high functioning 13-year-old autistic child reported:
He suffers badly from bullying which is largely ignored by the school in the hope that it will go away. When he objected to being bullied it was easier to exclude him than exclude 5–6 bullies. (Barnard et al., 2000, p. 9)

Lee (an undergraduate student of Mathematics and Computer Science at Oxford University mentioned in the preceding paragraph; Molloy & Vasil, 2002), was expelled from three schools by the age of 11 and had to be home-schooled because of his aggressive retaliation against his bullies. Jessica Peers (2003), who now holds a Masters degree in English Literature, was expelled from mainstream education when she was 12 and had to go to a boarding school for autistic children. Temple Grandin (Grandin & Scariano, 1986), who holds a PhD in Animal Science and is a college professor and a world renowned designer of animal stock facilities, was also expelled from a private mainstream school in Grade 7 and was sent to a boarding school for retarded children. For Dawn Prince-Hughes (2004), who holds a PhD in Anthropology and is now a university professor, bullying was just too much to bear by age 16, and she decided to quit school (as did some other autistic students; e.g., Stevens & Moffitt, 1988).

In their attempt to solve the problem, parents of some autistic children take a proactive approach and re-enroll their children in new schools where they hope their children would be less bullied (Asperger, 1944/1991; L. Jackson, 2002), whereas others—like Lee’s, Pierre’s, and some others’ (Pyles, 2004)—temporarily take their children out of school and enroll them in distance education or home-school them. However, as research on bullying has shown, these are only temporary solutions as they do not have much effect on reducing the likelihood of bullying in the new setting (Olweus, 1993). (As Olweus (1993) observed, “students who are bullied at a certain period of time also tend to be bullied several years later”; p. 28.) Indeed, as soon as Pierre, and some other children (e.g., Pyles, 2002), returned to school, the bullying continued, and Pierre continued to be blamed for his social difficulties, as were other autistic students (e.g., Andrews, 2006; Sainsbury, 2000; Grandin & Scariano, 1986).

Pierre’s next strategy—an attempt to please the adults (his parents and teachers)—consisted of trying to ignore the bullying. However, although this strategy has been often suggested by parents and teachers, and frequently used by students (W. Craig, Pepler, & Blais 2007), it is found to be useful only in mild cases (Horne, Orpinas, Newman-Carlson, & Bartolomucci, 2003); because as Hoover and colleagues (1992) put it, “the mildness of teasing is in ‘the eye of
the beholder’” (p. 13), it appears that it could not be predicted in advance for whom this strategy would work. In any case, it did not work for Pierre and he had to come up with another solution.

Pierre’s next strategy, skipping school—recognized in the psychological literature as an avoidance “coping style” (E. A. Skinner & Zimmer-Gembeck, 2007)—is also commonly used by bullied students (W. Craig et al., 2007; Glover et al., 2000; Kearney, 2008; Kochenderfer & Ladd, 1996; Reid, 1990) including autistic ones (Sainsbury, 2000). As Pierre put it, he skipped school “a lot” not because he was sick but “just because [he] couldn’t take it,” and because “just being [in school] was hard work.” Although it appears that Pierre’s parents supported this strategy, it ultimately proved counterproductive as it gave not only his classmates but also his teachers a new “reason” to bully him. Unfortunately, when, at the end of Grade 6, Pierre made the decision to stop skipping school, his parents did not take it seriously. Instead, they continued to actively advocate skipping school and, together with his siblings, inadvertently contributed to even more bullying. This misunderstanding from people on whose support he was relying, together with the increased amount of bullying, contributed to Pierre’ feeling of helplessness, which is commonly found among children who are chronically bullied (Due et al., 2005). Pierre said that it particularly bothered him that “there was nothing [he] could do” about bullying. As Asperger (1944/1991) put it, there is nothing a child alone can do. He wrote,

> The situation can be so bad that the mother must accompany the child to protect him from this sort of cruelty. The child may need a minder to the end of his school years and often beyond. (p. 79)

Although this kind of intervention may be considered outdated, contemporary literature on bullying agree with Asperger that dealing with bullying and its consequences is too big of a burden for the child alone (Besag, 1989; W. Craig et al., 2007; Rigby, 2000). As Besag suggested, “We cannot expect victims [of bullying] to cope alone. It is not their battle” (pp. xi–xii). She further argued that children need both training and support if they are to avoid the negative consequences of bullying. More recently, W. Craig and her colleagues (2007) similarly argued that, “Unless adults support children and youth, students are likely to do nothing and gain a sense of helplessness about their bullying experiences over time” (p. 474). This is exactly what happened to Pierre.
Without any “minders” or any other support or training, and after having exhausted his coping resources, there was nothing left for Pierre to do but to become physically ill—he was hospitalized with an ulcer. Becoming physically unwell, including becoming ill with psychosomatic illnesses is common among bullying victims (Due et al., 2005; Gini & Pozzoli, 2009; Nishina, Juvonen, & Witkow, 2005; Rigby, 2003) and is also sometimes described by autistic individuals (e.g., Andrews 2006; Sainsbury, 2000).

From an outside, third-person perspective, one could not immediately realize that the type of bullying Pierre was subjected to could have such profound and harmful effects. However, it is well known that the experience of victimization is subjective and that what matters the most in terms of psychological consequences are subjective evaluations of bullying (Graham & Juvonen, 1998). In other words, peer bullying does not affect all children in the same way. Hoover and his colleagues (1992) found that, although most children had been bullied at some point during their school years, only about 14% of those who experienced bullying had severe reactions to it. In their large study of bullied gifted students, J. S. Peterson and Ray (2006b) also found that whereas some students were bothered a lot others were not distressed at all. One reason why autistic children, including Pierre, could be so severely affected by bullying could be because the necessary emotional and cognitive resources for successfully dealing with bullying and its accumulated effects are, by definition, diminished in autistic children. Clare Sainsbury (2000) explains:

I have observed that children with Asperger’s seem to be particularly vulnerable to the effects of bullying, often being genuinely traumatized by what others would class as “mild” teasing. My personal theory is that our lack of social understanding reduces the psychological self-defense mechanisms available to us. Most children can interpret a comment like “You’re an idiot” in terms of the other’s motives (“he’s just being mean”, “they’re saying that to upset me” “she’s lying”) and so deflect it at least partially from a direct impact on their self-esteem. Often unable even to name what is happening to us as “bullying”, children with Asperger’s just absorb it, and either feel that we are idiots or end up expressing our pain by lashing out. (p. 86)

In addition, the frequency and the length of the bullying are also important factors: the more frequent and the longer the bullying lasts, the more severe are the consequences (Newman, Holden, & Delville, 2005; Rigby, 2000). The literature suggests that repeated victimization can overwhelm children’s coping mechanisms and contribute to the development of both physical
and psychological distress. It is well established in bullying literature that the psychological damage of chronic bullying can be enormous. The experience of being bullied by peers has been linked to a wide range of negative outcomes (in addition to reactive aggression and school absenteeism, mentioned earlier) including low self-esteem, post traumatic stress, anxiety, and depression (Hawker & Boulton, 2000; Mynard, Joseph, & Alexander, 2000; Olweus, 1993). Even as adults, victims of chronic school bullying are reported to be more likely to be depressed and to have poor self-esteem (Olweus, 1993).

Although literature on the psychological effects of bullying of autistic individuals is scant, the available evidence suggests that the experiences of being bullied are frequently associated with low self-esteem, post-traumatic stress symptoms, and depression (Attwood, 2004; Bashe & Kirby, 2001). From their own perspective, autistic individuals talk about “emotional” (Sainsbury, 2000, p. 85) and “psychic scars” (Dubin, 2007, p. 26) of childhood bullying. For example, Nick Dubin (2007) wrote, “Though I am a much different person now than I was then, some of the psychic scars [italics added] will be with me for life. These memories are, unfortunately, forever ingrained as a part of who I am” (p. 26).

Pierre’s “emotional scars” were certainly still evident each time he talked about his traumatic school experiences. At those times, he was unable to control his anger, which it seemed like he was re-experiencing while describing memories of events that angered him over 30 years ago. This kind of emotional dysregulation has not been associated with autism and is more consistent with consequences of trauma. Indeed, survivors of trauma are known to re-experience their traumatic memories as if they were happening all over again; that is, their memories are accompanied with the emotions experienced at the time of the remembered event including physical and motor changes (Brewin, Dalgleish, & Joseph, 1996; Ehlers & Clark, 2000). Moreover, from his clinical experience, Attwood (2004) reported that adults with Asperger Syndrome often exhibit clinical signs of Post Traumatic Stress Disorder. He explains:

[Adults with Asperger syndrome] have considerable difficulty understanding why they were the target so often, or the motivation of the children who tormented them. Their main way of trying to understand “why?” is to repeatedly replay the events in their thoughts. This can be a daily experience, even though the incidents occurred decades earlier. As the event is repeated in their thoughts, so are the emotions experienced again. Adults with Asperger Syndrome may require considerable psychotherapy to overcome
the deep and entrenched traumas caused by being the target of persistent bullying which often began in early childhood. They cannot easily forgive and forget until they understand why. (p. 19)

Importantly, as already mentioned, not all individuals who experience bullying or other trauma develop as extreme consequences as those of Pierre and some other autistic individuals. As Temple Grandin (1995a) observed, “I have learned by interviewing other people that when they think about past traumatic experiences they sometimes become overwhelmed with emotion. When I think about past traumatic experiences I seldom become upset” (p. 149).

Both bullying and trauma literature show both short- and long-term effects of bullying/other trauma effects are moderated by social support (L. M. Davidson & Demaray, 2007; Rigby, 2000). More specifically, the long-term effects of traumatic experiences are shown to depend on the interplay among three broad groups of factors: the nature of the trauma (e.g., its severity and duration), genetics (e.g., individual differences in emotional response styles), and the recovery environment (e.g., social support; Ballenger et al., 2004; Bowman, 1999; Brewin, Andrews, & Valentine, 2000). Moreover, research shows that perhaps the most significant predictor of the long-term effects of trauma is the post-trauma environment (Brewin et al., 2000) and that enhanced post-trauma support or other interventions can reduce the risk of long-term negative consequences of traumatic experiences (Ballenger et al., 2004).

It is a lack of social support that is immediately recognizable in Pierre’s personal history. It is interesting that Pierre himself has identified this lack of support as a still powerful trigger of anger. Because his teachers never understood the nature and depth of his social problems, they never provided him with any useful cognitive, or emotional, support, nor did they ever refer him for psychological assessment or counseling regarding either his lack of social skills or his subsequent traumatizing experiences.

Regrettably, it appears that Pierre’s parents did not take Pierre’s social difficulties, including his interpersonal conflicts, seriously either. This is understandable given that many parents see bullying as quite an ordinary part of growing up that allows children to “toughen up” (Rodkin, 2004, p. 101). In addition, many parents value their children’s independence and usually encourage them, boys particularly, to handle their affairs by themselves, which appears to be
what Pierre’s parents did. And even when Pierre directly asked them for support (as in at least two cases of being bullied by his teachers), they sided with the teachers (which is, of course, understandable given that they were educators themselves).

However, it is now clear that, given his lack of age-appropriate social and emotional skills, Pierre was assigned an impossible task in negotiating his own interpersonal conflicts (in a power-imbalance situation) by himself. It should also be noted that if Pierre’s parents refused to help him because they wanted to encourage his independence, they did not follow this approach consistently. For example, they did not honor his decision to deal with peer bullying by confronting it. Finally, because they did not recognize Pierre’s avoidance of school as a sign of psychological distress, and by further promoting this strategy even after Pierre recognized its counterproductive effects (in giving his bullies a new reason to bully him), they might have inadvertently contributed to his further distress.

9.3.3.4.1.1 Interpretive Summary

Pierre’s experiences, as well as those of other autistic individuals, testify how the educational system, instead of helping, can actually harm those who are different. More than one of his teachers not only actively bullied him but in doing so also modeled and indirectly gave permission to Pierre’s classmates to do the same, thus exacerbating his fear of coming to school and, in turn, largely contributing to Pierre’s long-term distress. Moreover, the school failed again by not alerting Pierre’s parents about the possible nature of his social difficulties.

Given Pierre’s love of learning and his high intellectual capacity, one would normally expect that his school experiences would be happier. Unfortunately, not only were his school days most unhappy, but even 30 years later, his school memories still cause him the same—or perhaps even greater—distress as the original events did. And this is not only the case for him, but for many other autistic adults.

Fortunately, with the end of high school, life became brighter for Pierre, as it did for many other autistic adults who chose, and could afford it, to continue their education. Pierre said that starting
university was a turning point in his life because there, “I was less troubled—I didn’t have to be in the presence of people who enjoy making my life difficult.” In saying this, he echoed Stephen Shore (2001) who referred to college as a “paradise” and “heaven” because “there was none of the teasing and ostracizing by fellow classmates that had followed me throughout my school years” (pp. 89–90).

9.3.3.4.1.2 Other participants

Like Pierre, 5 other participants selected their traumatic life experiences as their most significant life experiences. (See Table 10 for a summary of most significant life experiences.) Like Pierre, 2 other participants (Mike and Geoff) also chose their experiences related to being bullied. Sarah selected her experience of “getting left behind at school [after her class left for the field trip] [and] feeling abandoned [and] rejected” (Sarah); Alan, his car accident; and Jimmy, his uncle’s wedding when he “just freaked out [. . .] [and] started hiding from people.” Because all participants mentioned being bullied in their accounts, I will present in more detail and discuss only the participants’ experiences related to being bullied.

Mike. Like Pierre, Mike did not only choose his experiences of being bullied as the most significant experiences of his whole life, but he also devoted a lot of interview time to the topic. However, unlike Pierre, he reported that he was experiencing bullying throughout his life. He said that he began to get bullied as soon as he began going to school, that bullying was the worst in Grades 7 and 8, that it “got less” in high school and that it persisted even through working in the army. Also unlike Pierre, in addition to verbal bullying, Mike was also physically bullied, sometimes rather severely. He said: “I was bullied an awful lot as a little kid. I was very small. I had to defend myself, and nobody stood up for me. And basically, I got beat up a lot—an awful lot.” (It is important to note that, as already mentioned in the introductory section about Mike, his school documents support his account of being bullied. For example, a report from when he was 7 years old included a note about Mike’s dependency on his parents for protection “from hostile environment [with] which he cannot cope.”)
### Table 10 Summary of Participants’ Most Significant Life Experiences

<table>
<thead>
<tr>
<th>Valence</th>
<th>Category</th>
<th>Subcategory</th>
<th>Experience</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive</td>
<td>Personal dev.</td>
<td>Life transition</td>
<td>moving away from home (P, O); starting working (S, H); joining army (M)</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discovering passions</td>
<td>music (G, J); photography (H)</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Autism</td>
<td></td>
<td>getting diagnosed (O; A); reading a book about (A)</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Achievement</td>
<td></td>
<td>“the production of the [village] map” (O); getting accepted at a music</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>academy (S)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td></td>
<td>beginning of spirituality (G); connecting to the Internet (P) a</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>Intimate</td>
<td>relationships</td>
<td>being married (M); living with a girlfriend (J)</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>dev.</td>
<td>Group</td>
<td>relationships</td>
<td>starting to attend autism support groups (H)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td>Social</td>
<td></td>
<td>being bullied (P, M, G); being left behind at school (S); event that</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Trauma</td>
<td></td>
<td></td>
<td>marked the emergence of “hiding from people” (J)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physical</td>
<td>car accident (A)</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td>24</td>
<td></td>
</tr>
</tbody>
</table>

Note. A = Alan; dev. = development; G = Geoff; H = Howard; J = Jimmy; M = Mike; O = Orville; P = Pierre; S = Sarah.

aThis was both personal and social experience.

Mike’s worst bullying incident, which he considered as one of the most significant events of his life, was a severe beating when he was about seven years old and was left bleeding in a snow bank miles from his home:

Where we lived to where I had to go [to school] was a mile and a half. And I was a little guy. And in the winter time, it was pretty tough because there was no bus service—one and half . . . two miles, actually. It was quite far. And I had to walk. And I remember [pause] more than . . . well, several occasions—probably three, five times . . . I used to get beaten up all the time. And one time I . . . a brother and sister team . . . they beat me up pretty bad. And they kicked me, they punched me in the face, they kicked me in the
crotch, and they left me basically for dead in the snow bank. [...] And I had... my face was all... [lifts his hand from the table and drops it back making a sound] my face was all smashed in, like, punched in... and blood and [the same movement and sound] all my clothes and all that. It was winter time, it was very cold—I still remember that cause I had to walk far away home, and when I got home it was dark. [the same movement and sound]

Mike continued to be bullied in his later school years—physically, verbally, and by not being accepted. He believed that bullying significantly contributed to his deep feelings of unhappiness and depression in Grades 7 and 8, which he considered the worst period of his life:

I had a hell of a time there [in his new school]. Oh man! I had a hell of a time—I still... was a very dark, dark period of my life—very dark. And... [pause] I had hardly any friends. [...] It was really tough because I was not accepted. [...] I was pushed around. I got punched in the face, at times. I used to be embarrassed all the time.

Like Pierre, Mike was not only bullied by his peers but also by his teachers. He described the following incident, which occurred during the same time period:

I was in a wood-working class, and the guy [teacher] was just so... he was so ignorant [...]. And all the other boys could do... [starts drawing on the back side of the life-line sheet] he wanted a dimensional drawing of, like, a wheel or something, of a circle, and I didn’t know how to do [it], so he embarrasses me in front of all the other boys. He said, “You don’t know how to do that? Are you stupid? You’re stupid, aren’t you?” [emotionally] And everybody’s laughing. And... but [what] he basically wanted... was something like this [shows the drawing], but I couldn’t do this. I didn’t know how to do it, and he dressed me down—expression. He embarrassed me in front of... and I was just a loser, and all stuff cause I couldn’t do this—I couldn’t do a simple drawing like this [pointing to the drawing].

Mike continued to be bullied in high school, where he was mostly teased about his clothes and puffy hair. Compared to his Grade 7 and 8 experiences, Mike found teasing relatively easier to deal with—although not all the time. He described one high-school teasing incident, to which he responded physically and for which he got suspended for three days, in the following way:

I remember, I used to... [pause] I dressed differently. I’m sort of the opposite of what... I wasn’t sloppy. I had very puffy hair, but... I used to wear ties [lifts his hand from the table and drops it back making a sound]. I used to wear ties all the time. [taps the table several times] And, I remember one time, I was going down the hallway, [lifts his hand from the table and drops it back making a sound] and it was before class, [taps the table several times] and one of the guys, hmm, said to me, “Ooooo, n-i-i-i-ce t-i-i-i-i-e,” you
know what I mean . . . started to go, “Ooooo, that’s so pretty,” right—like that. Hmm, he started going, like, “This is my tie,” and he’s pulling on my tie like this [shows], so I hauled off, and I punched him in the nose. [pause] And it was reactive, and we both got expelled from school cause he then punched me.

Asked whether he remembered how he felt when he was bullied in school, Mike replied, “Neah. I felt like . . . [pause] I felt like I was worthless. I felt like trash. Like, I . . . like, you know, people can just beat me up.” Mike believed that his bullying experiences had a huge impact on his confidence: were he not bullied, he said, he “would be more confident.” When asked how he felt about his bullying experience now, he replied,

Ekhh, I’m just talking about it. I can’t do anything about it, so it doesn’t bother me anymore. Ekhh. I’m too old for that [exhales loudly; chuckles]. I’ve gotten over a lot of stuff. I just carry on. I just work with stuff that’s in the past. I can’t do anything about it. [exhales loudly]. That’s a lot of what has happened to me. I’ve had to learn how to cope on my own strategies.

Unlike Pierre, Mike said that because he was smaller than other students, he almost never fought back. When he tried, it did not work, as his above-quote demonstrates. Instead, he said, he usually relied on help from his siblings and their friends—when they went to the same school. At other times, he tried to minimize contact with others by always being late for school. In contrast to Pierre’s experience of lack of support, Mike always felt that his parents were protecting him as much as they could. In fact, as the school records indicate, at the beginning of his schooling, Mike almost exclusively relied on the help of his parents in coping with “hostile environment.”

It is also interesting that unlike Pierre, Mike said that his peer bullying experiences thought him an important life lesson, “that not everybody is not [sic] nice. There are nice people out there and there are people that are just being mean, but most people are nice.” Therefore, the best thing to do, he thought, was “just avoid those [mean] people or be nice.” Indeed, these were the strategies Mike used most of his life, and he felt bad when he could not apply them. For example, he still regrets physically defending himself against the bully who teased him about his tie: “I should’ve used my words to explain how I felt,” he said, “but I did hit him” [. . .] I didn’t want to do it, but I had no way to . . . I should’ve just used my words.”
Unlike Pierre, who stopped being bullied after high school, Mike continued to experience bullying throughout his post-secondary army training, as well as at his work, where he is belittled. Moreover, as already mentioned, he also felt that he was not socially accepted at his workplace, which he found particularly hurtful. He believed that the main reason behind his nonacceptance by others lies in his autism—and that was the main reason why he said that autism “hurts.” He expressed this sentiment best when he talked about a perfect world: he said that its main feature would be that everybody would be accepted for who they are:

> Everybody just got along with [lifts his hand from the table and drops it back making a sound] everybody. They accepted everybody. Everybody was somewhat the same. They accepted you [the same movement and sound] for who you were. You would find love much easier. But it would also be fair—people would be fair to you and you would be fair with them all the time, and, it would be . . . I guess, that sounds like utopia.

**Geoff.** As for Pierre and Mike, bullying played an important role in Geoff’s life. He also placed his experiences of being bullied among the most significant experiences of his life. Like Mike, Geoff also experienced his worst bullying in Grade 7. When choosing his most significant experiences, he said, “I will just call this Grade 7. There we go.” Things that made this year special included “bullying, rejection, feelings of difference, coupled with, you know, my first sexual awakenings.” As already described, bullying and rejection played a major role in Geoff’s realization of being negatively different than others. Like Mike, he also noticed that at least one reason for being bullied was his unfashionable way of dressing. Like Pierre, but unlike Mike, Geoff was not physically bullied, except on one occasion when he was pushed into his locker. His most painful experiences included verbal and relational bullying. On one occasion “someone pinned a ‘kick me’ sign on my back and I remember walking down the hall and being laughed at.” His Grade 7 school experiences were so painful that he, like Pierre, did not want to go to school. However, unlike Pierre, he did not skip school and considers himself courageous for not doing it. Indeed, he considers courage his greatest strength, for which he gave the following example: “When I was in Grade 7, and I was being bullied, you know, and [long pause], you know, I didn’t wanna go back to school every day, but I did. And I faced [it].” Nevertheless, at the beginning of Grade 8, as bullying continued and he had more and more difficulty dealing with it, upon his parents’ suggestion, he changed schools. Although he experienced less teasing in the new school, nonacceptance and rejections continued.
Like Mike, Geoff also believed that bullying, and rejection in particular, significantly contributed to his further withdrawal from already limited social interactions, as well as to his subsequent feelings of unhappiness and depression, and eventual “emotional shut-down.” Asked how he felt then, he replied,

I think I was bewildered. I didn’t understand why I was being treated so badly, and eventually, I became depressed. Because, you know, I just, sort of, had these rejections pile up, and pile up, and, really, what it led to was the emotional shut-down.

He also said, “I had no impulse to fight back or try to change things; I just wanted to run and hide, which, emotionally, I did.” Geoff also believed that his bullying experiences had a very significant influence on his later life: “There is a very persistent fear of rejection, expectation of rejection that comes from what I’ve experienced in this time.” He elaborated,

The persistent theme of rejection, and of feeling clueless with, you know, dating, and that has gone from here right through. And it’s still a really big problem, and I think a lot of the expectations I have—both of myself and of, you know, potential partners—are colored by those experiences. Very much, in fact. So I sense that some of my future work might be trying to undo some of that, or correct it, or something. I don’t know how, but . . .

It is also interesting that, as previously mentioned, Geoff said that writing about his bullying experiences in his autobiography helped him get over them, as well as forgive his bullies. He said that, in the process of writing,

I realized, you know, that they . . . that we were all, you know, insecure and in this weird sort of time in adolescence, just getting into puberty, and [pause], you know, they were coping with it, you know, with sort of bravado, and this sort of thing, but they were as scared to death as I was inside. I didn’t know that until much, much later. And that helped me sort of forgive them and feel, you know, feel better about it.

Orville. During the interview, Orville also made several references to bullying. For example, he mentioned “the bullying going on in school,” the students in high school being more “belligerent [toward him] than they were in elementary school” and “even one teacher was trying to interest me in self-defence at the time.” However, these remarks were embedded within Orville’s longer replies, and I did not follow them up until after the interviews; in the phone interview, he said that he was bullied “all the time”: 
In the cafeteria [other students] would not let me sit. They would say, “Don’t sit here. It’s reserved for my friends.” In a hallway, they called me names and pushed me—all the time, constantly. It wasn’t just one-day event.

As already mentioned, in another, e-mail follow-up, in which I asked Orville about his realization of being different from others, he also wrote about his bullying experiences. He referred to his being bullied as “daily routines” of some students. Moreover, like Pierre and Mike, Orville also mentioned being bullied by his teachers. When writing about the experiences that contributed the most to his realization of being different from his peers, he recalled an incident in which he was bullied by one of his teachers for—from his perspective—no obvious reason:

One morning, the teacher was absent when school started, and the other pupils began to move around and tell jokes, when, suddenly, the teacher appeared in the classroom, turned towards the first row of desks (where I was seated at my desk), and yelled (while pointing towards me) “You! Get out and stand in the hall for the rest of the day!” When I turned to see if she was pointing to another pupil, she yelled “Don't look at anyone else! I mean you! Get out into that hallway NOW!” I left the classroom, and to this day, I have no idea what made the teacher do that towards me. That made the other pupils refrain more-and-more from interacting with me, even during recess and after school.

When asked how he felt when he was bullied, Orville said, “Rejected would be a mild word—isolated, couldn’t communicate.” As already noted, as for Mike, these feelings of “rejection” and isolation were not part of Orville’s school experiences only; they accompanied him throughout his life. Indeed, like Mike, Orville also talked a lot about not being accepted—even being actively rejected and “dismissed”—in adulthood. He said that his ideas at group meetings are never accepted (or even taken seriously): “I find there’s just lack of acceptance or respect right there instead of . . . dismissing, that’s the word . . . that’s the term that comes to mind so often in life, as though as my ideas are automatically dismissed.” He also mentioned how he often felt rejected when he attempted to chat with other people. He said, “[People] don’t seem to be willing to accept me. They seem to feel [as] though they have to exit from me.” He gave the following example:

And then, couple of minutes later, the person I’m chatting with [says], “Oh, I have to be going, I’m late already,” look at their watch or something, and, “Nice chatting with you,” and they leave, and yet ten minutes later, I look down the room and they’re still chatting with
someone else, and I think to myself, Why were they in such a hurry to leave me because they were late, and yet they’re still chatting with somebody [chuckles]. It just doesn’t add up in my mind. [chuckles]. Like, “Why would a person tell me they have to leave if they don’t have to leave?”

Like Mike, Orville also made frequent references to his wish of one day people accepting him as he is. For example, he remarked, “I’d like to find somebody else who is willing to accept me,” and “[I’d like] when I do communicate with people [that] they have a far better acceptance.”

**Howard.** Howard was also bullied in school. However, unlike other participants, he did not like to talk about these nor, as already mentioned, any other negative experiences. Nevertheless, he did say, “Oh, my friends used to tease me.” (It should also be remembered that Howard did not report having any friends at school; so he probably meant peers when he said friends.) Asked whether he remembered any particular teasing incident, he replied, “I don’t remember any teasing in particular.”

As already mentioned, like Pierre and Geoff, Howard also believed that his bullying experiences contributed to his realization that he was different from his peers. It is interesting that, like Geoff, Howard also expressed some empathy for his bullies. Moreover, he made an attempt to defend them. He said, “They [his “friends”] didn’t understand [that he was autistic]—nobody knew. Nobody knew back then.” Like Geoff, it also appears that Howard was bullied less when he changed schools. He attributed this change to being loved—and thus protected—by principals and teachers in the new school:

Later they [his “friends”] knew. In later years [starts tapping], they knew they were in trouble if they tried anything because, officially, the principals loved me—that’s the way I have to tell you. The principals loved me. [stops tapping] And they knew [that] all the teachers loved me. They knew they would be in trouble if they ever tried anything. And this was the difference, but this was at different school.

**Sarah.** Like Mike and Orville, but unlike Pierre, Sarah also talked about not being accepted and even being actively rejected by her peers. For example, Sarah remembered “being close with someone, and then they would decide not to be my friend anymore,” which made her feel “very hurtful [and] rejected.” Although she did not talk a lot about her experiences of being bullied (she was similarly concise with all other topics), she made one comment from which we can infer that she was verbally bullied, at least before high school: “[High school] was a very good
environment, I’d say, for me cause . . . like, students didn’t really make fun of me. I got quite, like, close with my classmates and just felt very safe and secure.” From her reference to not being “really” made fun of, we can also infer that, as was in Mike’s case, although the bullying probably decreased in high school, it did not stop entirely.

**Alan.** Alan also said that he was “teased a lot” in school, but he did not talk much about these experiences. He also mentioned feeling that he did not fit in, which, at least in part, could be interpreted as nonacceptance, and thus bullying.

**Jimmy.** Although Jimmy did not spontaneously mention being bullied, when asked about it, he remembered that he was teased when he was younger: “I don’t think I was ever really shoved around or bullied physically. It was just more kinda getting picked on.” He also remembered “people trying to sort of push me around in high school.” For example, he said, “I remember someone trying to take my seat once in [front of] the principal’s office and I said no.” It is also interesting that he said that he was empathetic towards victims of physical bullying:

> I do remember kids kinda being mean and saying stuff . . . I was always really sensitive to bullying, and I used to feel really empathetic towards other kids that were [bullied], when I saw it. It used to really upset me. I remember lying in bed crying at night when I was a kid because of watching some kid get beat up.

### 9.3.3.4.1.3 Interpretive Summary

Like Pierre, all other participants in this study reported being bullied during their schooling.

**Types of experienced bullying.** Six participants (all except Jimmy and Alan) made spontaneous references to direct types of bullying (i.e., verbal and/or physical bullying), and the same number of participants (all except Pierre and Jimmy) also made references to indirect types of bullying, such as exclusion and rejection. Like Pierre, 2 other participants, Mike and Orville, also reported being bullied by their teachers. The participants reported the following types of bullying:

1. **Physical bullying**—ranging from pushing to kicking, punching, and getting beaten up—was reported by 3 participants (Mike, Orville, and Geoff). However, it is important to note that
the severity and duration of the bullying that these participants experienced was very different. Thus, whereas Geoff had a clear memory of only one instance of physical bullying, Mike and Orville were physically bullied repeatedly over many years. Likewise, whereas Orville only mentioned being pushed, Mike talked about being kicked, punched, and beaten up. The participants’ remarks about being physically bullied include “[He] shoved me into my locker” (Geoff); “They [. . .] pushed me—all the time, constantly” (Orville); and “They kicked me”; “They kicked me in the crotch”; “They punched me in the face”; “My face was all smashed in, like, punched in . . . and blood . . .”; “They beat me up pretty bad”; “They left me basically for dead in the snow bank” (Mike); “I used to get beaten up all the time”; “I got beat up a lot—an awful lot” (Mike).

2. **Verbal bullying**—ranging from occasional to constant—was reported by all participants. References to this kind of bullying included “[In high school] students didn’t really make fun of me” (Sarah); “Friends used to tease me” (Howard); “[I was] kinda getting picked on” and “People trying to sort of push me around” (Jimmy); “I was teased a lot” (Alan); “They called me names [. . .]—all the time, constantly,” and “Other peers would tease me with questions such as ‘Who do you think you are, smart alec?’ and other taunts that got progressively more into foul language over the years” (Orville); and “I switched schools because I was really getting bullied” (Geoff; by “bullying,” Geoff mostly meant verbal bullying and rejection.)

3. **Rejection**—which was, like nonacceptance, expressed both directly and indirectly—was mentioned by 3 participants. References to this kind of bullying include: “I felt very hurtful, rejected” (Sarah); “I felt rejected” and “I just, sort of, had these rejections pile up and pile up” (Geoff); “[I hope] I can communicate without this backlash or without this rejection outright” (Orville).

4. **Nonacceptance**—which was sometimes expressed explicitly, but most of the time was implicit in participants accounts—was part of all participants’ lives. Direct acknowledgement of their nonacceptance includes the following remarks: “I was not accepted” and “I didn’t fit in” [Mike]; “They don’t seem to be willing to accept me” (Orville), “I didn’t fit in” (Alan). Implicit indications of nonacceptance were often found in participants’ statements about their hopes and wishes that one day they will be (more) accepted, as in “I also hope that I will
experience, maybe for the first time [. . .] being accepted instead of being rejected” (Geoff); “[I hope they] understand me and try to accept me for what I am even though that’s going to be quite difficult to do, you know” (Alan); “I’d like to find somebody else who is willing to accept me” and “[I’d like] when I do communicate with people they have a far better acceptance” (Orville).

The above-compiled list of types of bullying experiences of autistic individuals is consistent with the previously reviewed autobiographical literature on autism. Almost all autobiographical accounts of autistic individuals contained references to verbal bullying (Grandin, 1995c; Dumortier, 2004; N. Jackson, 2002; Shore, 2003; Tammet, 2006; for an exception see, Holliday Willey, 1999); many also included very dramatic descriptions of physical bullying (e.g., Andrews, 2006; Boswell, 2008; Gerland, 1997; Joliffe et al., 1992; Prince-Hughes, 2002; Sainsbury, 2000) as well as nonacceptance (e.g., Dumortier, 2004; Spicer, 1998b). However, it is important to note that although many autistic individuals wrote about not being accepted for who they are, some autistic adults feel accepted as they are (e.g., Grandin, 1995c; Grandin & Barron, 2005; Robison, 2008; Shore, 2001)—but only to the extent to which they behave as everybody else (e.g., Dumortier, 2004; Spicer, 1998b).

**Chronology of bullying.** It is interesting that like Pierre, 2 other participants who experienced the most difficulty with bullying, Mike and Geoff, also reported that the bullying was most difficult to deal with in Grade 7. Pierre said that whereas his response to bullying before Grade 7 was either ignoring or “just [saying] angry things,” when he could not ignore it, in Grade 7 “[he] got to the point that [he] started hitting people.” Likewise, describing the same time period, Mike used the following descriptors: “hell of a time,” “it was really tough,” and “a very dark, dark period of my life—very dark.” Geoff expressed his feelings best when he said that he did not want to go back to school every day and “face” bullying.

Most participants reported that bullying diminished in high school and half of the participants (Pierre, Sarah, Jimmy, and Howard) did not make any mention of being bullied (including not being accepted) in adulthood. However, 2 participants, Mike and Orville, continued to be bullied—verbally and through nonacceptance and rejection—in their adulthood; and 2 other participants, Geoff and Alan, continue to feel not accepted. Mike and Orville were particularly hurt by not being
socially accepted in adulthood. They expressed their sentiments best by including social acceptance for everybody as the main component of a perfect world.

**Reactions to being bullied in school.** The participants’ reactions to their experiences of being bullied varied from relatively mild to very severe. Thus, on the one hand, although Alan and Jimmy reported being teased, they did not make much of it. However, Sarah reported having immediate negative reactions (i.e., negative feelings such as hurt, sadness, and feeling of rejection). Moreover, as already mentioned, from the psychiatric report it appears that she also had some longer-term negative consequences such as a decrease in self-confidence in regard to her social interaction skills and increase of social anxiety. However, it is interesting that during the interview Sarah did not mention any subjectively felt long-term negative consequences of her experiences of being bullied. One way to account for this discontinuity is to consider that Sarah (a) mentioned being significantly less bullied in high school; (b) did not mention any bullying in college; and (c) reported making friends in college, which collectively could have helped her heal her bullying wounds.

On the other hand, Mike, Geoff, and Orville—for whom it appears that being bullied was a daily school “routine”—reported that they believed that the bullying had significant adverse effects on their psychological wellbeing, both then and now. For example, Mike and Geoff believed these experiences diminished their self-confidence, both short- and long-term, as well as that they significantly contributed to their feelings of unhappiness and development of depression at the time they endured the worse bullying. Mike and Geoff’s placements of their experiences of being bullied as either the most or among the most important experiences of their lives, respectively, in terms of their influence on becoming the persons they are now is consistent with their beliefs about the long-term effects of bullying on their lives. Although Orville suggested that he experienced some of the same consequences of bullying, such as depression, he was not referring specifically to his self-confidence; rather, he said that “[nonacceptance] lead to living a life as a ‘loner,’ with very few opportunities for human interaction for decades.”

It is also interesting that like Pierre, at least 1 other participant (Orville) seems to continue to feel a lot of bitterness about his bullying experiences. On the other hand, 3 participants (Mike, Geoff, and Howard) seemed to have, as Mike put it, “gotten over” their experiences. For example, Mike said that he was “just talking” about them (i.e., without getting upset) and “I just carry on.”
Likewise, as already mentioned, Geoff, said that after writing about his most painful bullying experiences, he was finally able to accept these experiences and feel better both about himself and about his bullies.

Although Howard’s subjective reactions to what he called teasing by his “friends” are difficult to evaluate because he declined to discuss his teasing experiences, they, nevertheless, deserve some consideration. The first time Howard mentioned being teased, he immediately added, “I don’t usually talk [about] my negative stuff.” (He later supported this claim by saying that “everybody knows” that he does not “like” to talk about his negative experiences.) Consequently, during the interview, he usually answered questions aiming to uncover such experiences with I don’t know and I don’t remember. One way to account for this answering pattern is to accept Howard’s answers at their face value. However, it is also important to note that during the interview, Howard made several remarks (e.g., “Nobody could live with me” and “Nobody would live with me”) that, at least to some interpreters, might suggest a low level of self-confidence. If so, as already mentioned, Howard’s refusal to talk about and remember his negative experiences may be his way of coping (i.e., protecting himself from being psychologically harmed by his negative experiences with teasing and rejection). This interpretation may have potential support in Mike and Geoff’s claims that their bullying experiences significantly influenced their self-confidence. Nevertheless, in contrast to Howard, Mike and Geoff believed that talking and/or writing about their negative experiences was more beneficial than trying to keep them hidden.

It is interesting that Pierre was the only participant who expressed his anger toward this bullies. Other participants reported feeling hurt (Sarah and Geoff), sad (Sarah); embarrassed (“I used to be embarrassed all the time,” Mike); rejected (Geoff, Mike, and Orville), as well as feeling “bad,” “worthless,” and “like trash” (Mike). During periods of the most intense bullying, Grades 7 and 8, Mike and Geoff also expressed being “emotionless” and in “emotional shut-down, respectively. It is also interesting that, looking retrospectively, 2 participants, Geoff and Howard, also expressed some empathy for their bullies. Thus Geoff said that he now understand that bullying was his bullies’ way of dealing with the same issues he was dealing with, whereas Howard said that he forgives his bullies because “they didn’t know” that he was autistic.
The range of reactions of this study’s participants to bullying is consistent with the general literature on bullying, which suggests both huge individual differences and a variety of adverse both short- and long-term effects of bullying (Rigby, 2003). It is also consistent with autobiographical literature on autism (Andrews, 2006; N. Jackson, 2002; Sainsbury, 2000). For example, like Mike, who said that he felt worthless, Nita Jackson (2002), who wrote that she was “bullied into silence” (p. 50), described a similar sentiment about the effects of bullying on her self-esteem:

I felt like less of a person and more of a corpulent object to be abused. I had the personality of a slug on valium, never uttering a word to my peers except “sorry”. I actually didn’t feel worthy to be liked. (p. 24)

**Strategies for dealing with bullying.** The most common way of dealing with bullying amongst the participants appeared to be *ignoring*, which was either explicitly or implicitly contained in the accounts of all participants. Pierre, Mike, and to some extent Geoff also used *minimizing contact* with their bullies, either by skipping school (Pierre), always being purposefully late for school (Mike), or changing schools when bullying became too much to deal with (Geoff). It is interesting that, with the exception of Mike’s one aggressive reaction, Pierre was the only participant who tried to use *aggression* as a defense against bullying.

A final strategy mentioned by this study’s participants was eliciting (or obtaining) help from others, which was, in addition to Pierre, also mentioned by Mike and Geoff. For example, Mike said that during recess, whenever possible, he tried to be close to his siblings and their friends so that, if need be, they could protect him. Moreover, unlike Pierre, whose attempts to elicit help from his parents with regard to bullying were unsuccessful, according to school documents, Mike obtained such help from—at least at the beginning of his schooling. It should, however, be noted that Mike’s parents’ help was viewed unfavorably by school personnel, which, as already mentioned, at least in part, could explain why Pierre’s parents (both of whom were educators) were reluctant to interfere. When considering the different responses of Pierre and Mike’s parents to their children’s bullying problems, it is also important to recall that whereas Mike—who was, in addition to the verbal bullying, also physically bullied—had physical evidence of bullying, which was not the case with Pierre, whose bullying left only invisible emotional evidence.
Like Mike, Geoff also received some help from his parents with regard to bullying when he was in Grade 7, when they suggested Geoff change schools in order to avoid bullying, which Geoff did, and which worked. It is, however, interesting to note that although, like Pierre, Geoff was not physically bullied, his parents gathered enough evidence to suggest that they needed to do something to help their son. Of course, without knowing which evidence they relied on, these differences in responses are difficult to interpret. However, based on Geoff’s mention of his feelings of depression in Grade 7, it is reasonable to assume that his parents’ reaction could have been, at least in part, prompted by signs of depression that Geoff exhibited.

The strategies of this study’s participants were similar to those used by other autistic children. For example, in their autobiographies, other autistic individuals also talked about ignoring (Dumortier, 2004; N. Jackson, 2002; Shore, 2003; Tammet, 2006), hiding (Fleisher, 2003; L. Jackson, 2002; Prince-Hughes, 2004), changing schools (e.g., Jackson 2002), responding physically (e.g., Gerland, 1997; Grandin & Scariano, 1986), and obtaining help from others (Jackson 2002). It is interesting that whereas responding physically worked for Gunilla Gerland (1997), who wrote that after her return of aggression, “No one dared bully me any longer” (p. 161), it did not work for Temple Grandin, who, like Mike, was expelled from school as a result. The strategies of this study’s participants were also consistent with those used by other victims of bullying (Glover et al., 2000).

**School's response.** A final observation concerns participants’ views about their schools’ responses to them being bullied. Like Pierre, most other participants did not mention receiving any specific help from their teachers with regard to dealing with bullies, nor do their references to repeated incidents of being bullied suggest that their schools did anything to prevent it. In fact, Orville is the only participant that mentioned a teacher who “was trying to interest [him] in self-defence.” However, as Orville pointed out, given that at that time there were no such opportunities offered by the school, nor anywhere in the small town in which he lived, the teacher’s proposal cannot be considered a serious attempt at intervention, but rather, as Orville suggested, an acknowledgment that he had observed the bullying. Nevertheless, Orville perceived his teacher’s suggestion as helpful and considered himself lucky that he had “such [a] supportive” teacher. Given Orville’s descriptions of some of his other teachers’ behaviors
towards him, which are consistent with teacher bullying, it is understandable why Orville interpreted this teacher’s behavior as supportive.

Although Howard did not mention any specific help that he received with regard to being teased in one of his schools, one of his remarks about bullying deserves special attention. Howard said that when he changed schools, he was not teased any more. He attributed this absence of teasing to his new teachers’ and principals’ “love,” which he perceived as a deterrent for any potential bullying. Like Howard, Geoff was also bullied in one school but not in another. Taken together these accounts perhaps point to an important role of school culture for bullying, which is frequently reported in bullying literature (e.g., D. J. James et al., 2008; Nansel et al., 2001). Most importantly, they challenge the view that autistic children are “natural targets” for bullies and suggest that bullying is not only preventable, but also that a proper school curriculum must include a larger social component than it did in the past to prevent bulling.

As the accounts of this study’s participants suggest, their schools failed to not only protect them from bullying and provide them with adequate strategies for responding, but they also failed to make any steps towards the prevention of any further negative reactions to the bullying that the participants could have developed. As bullying literature clearly suggests, unless victims of bullying are provided with adequate post-bullying help, there is a high probability that they will experience at least some negative consequences, ranging from a sense of helplessness and low self-esteem to depression (Craig et al., 2007; Rigby, 2003).

Inadequate responses of the participants’ schools with regard to bullying are consistent both with autobiographical literature on autism (e.g., Andrews, 2006; Grandin & Scariano, 1986; Shore, 2003) and with bullying literature (D. J. James et al., 2008).

9.3.3.4.2 Moving away

In contrast with the negative experiences associated with bullying, for his second most important life experience Pierre selected a positive experience—moving away from home for the first time at age 28. Pierre moved out, together with his sister, when he began his PhD program in another
city. For Pierre, living away from home meant, first and foremost, “more independence.” It was also “a time of new experiences,” which Pierre enjoyed. Likewise, Pierre also enjoyed his independence when he spent a year abroad alone researching for his PhD thesis, which he described as the happiest time of his life, confirming that the experienced sense of independence was both very important and very enjoyable to him.

Although some other autistic adults regard moving away and studying at colleges and universities as the happiest times of their lives (e.g., Szatmari, Bartolucci, & Bremner, 1989), others find this transition particularly challenging. One of the challenges that autistic individuals find extremely difficult to navigate is the adaptation to a new physical environment (Attwood, 2006; Kanner, 1943; Szatmari et al., 2006). As already noted, autistic individuals have a high need for “sameness of the environment” (Kanner, 1943, p. 238) and, consequently, they resist and avoid change. Indeed, many autistic autobiographers (e.g., Grandin, 1995c; Holliday Willey, 1999; Prince-Hughes, 2002) described the transition to college/university as very difficult. For example, Temple Grandin wrote,

The really big challenge for me was making the transition from high school to college. People with autism have tremendous difficulty with change. In order to deal with a major change such as leaving high school, I needed a way to rehearse it, acting out each phase in my life by walking through an actual door, window, or gate. (p. 34)

From this perspective, Pierre’s—as well as some other autistic individuals’ (e.g., Shore, 2001)—not having any difficulty with moving away seems unusual. However, this anomaly, at least in part, could be explained by clinical observations (e.g., Gillberg, 1992; Wing, 1981) and autobiographical accounts that suggest that autistic individuals differ with regard to the level of difficulty they have with change. Moreover, these accounts also suggest that the clinical picture of autistic individuals changes with time and that by adulthood, some, but not all, autistic individuals no longer have difficulties with change except when under stress.

Another challenging aspect of moving away reported by autistic individuals is dealing with the new social environment, or the lack thereof. Moving away from home also means having to establish new relationships, and, as already noted, that is one of the core difficulties of autistic individuals (APA, 1994; Baron-Cohen et al., 2005). Indeed, after they moved away, many
autistic adults faced total, or near total, social isolation and could not establish any satisfying social relationships for years (e.g., Holliday Willey, 1999). However, because Pierre moved together with his sister, he did not face quite the same problem as those other autistic individuals, and it is possible that this one solid relationship met his social needs at the time.

9.3.3.4.2.1 Other Participants

Orville. Like Pierre, Orville also selected his experiences associated with moving away from home as his second most important life experience, to which he referred as “first moving away from home [and] being on my own.” Like Pierre, Orville was also twenty-eight when he first moved away. However, circumstances of his move were very different than those of Pierre. Unlike Pierre, whose moving away was his choice, Orville moved because he was told that he had to: His parents decided to sell their house and just told Orville, without “a warning,” “At the end of this month, we’re moving 27 miles away from here. By then, you have to find a place of your own.” Orville said, “I felt surprised by that.” Moreover, he said,

First, it was kind of a shock to [me] that they made all these plans apparently with my older sister to move [. . .] without discussing with me or anything and then [taps table] just come to me and tell me, “Here, we are moving to this place by the end of this month,” without any other warning. That’s what was the shock about it that they should have brought the topic up before then, but they didn’t at all.

Asked what moving away meant to him, Orville replied,

It meant that I didn’t have to be accountable for everything I did, all the time, every moment. Whereas before then, living with my parents, it was not much different than when I was a youngster or anything else. Now I was 28 at the time, [and I] had to explain everything—why and all that—to them. Whereas once I got off on my own, I could begin to do things on my own without having to give an explanation all the time to somebody.

Indeed not having to answer his parents’ questions any more felt like a relief to Orville. However, moving away for him, unlike for Pierre, was also associated with some negative experiences:
[I] felt a sense of relief. The trouble was, at the time I still didn’t have transportation other than a bicycle, and I still didn’t have a job, so I still felt concerned about my finances, and [it] took quite a while to build up funds.

Nevertheless, Orville felt that moving away was overall a positive change, because it helped him “grow up, and mature, and advance, and expand”:

It released me from what I would call the “child bondage,” of being dependant not just on parents financially—all children are—but [also] on parents’ beliefs, and that. Before then, I always had to answer to them, but after that, I could live my own life without having to answer “What [are] you doing this for?”

**Mike.** Mike selected “joining the army” as his most important life experience. However, although, at the first sight, this experience appears similar to that of Pierre and Orville’s moving-away-from-home experiences because it also includes a component of independence that both Pierre and Orville emphasized, Mike’s reasons for choosing this experience were rather different. For him, joining the army was important because it provided him with “more organization,” which he felt he needed:

I was scattered. I had . . . I was disorganized. I couldn’t stay on time on anything. But [army] gave me more organization. I knew . . . okay, you have to be here [lifts his hand from the table and drops it back making a sound] at this time, you have to put this on [repeats the hand movement], you have to wear this [the same movement and sound], you have to . . . [pause] hmm, you have to act this way. [. . .] The army tells you when to get up. They tell you when to go to bed. They tell you everything. [lifts his hand from the table and drops it back making a sound]

In addition, being in the army was also important for Mike because it provided him with security—both financial and social: “I felt security from it. [. . .] And I knew that was secure. And I knew that I would probably be [pause] accepted to some degree.” He also said, “And that’s one of the good things about the army . . . because they . . . people take . . . even though you may not be completely socially accepted, you’re still [pause] taken care of.”

**Sarah.** As her third most important life experience, Sarah also chose an experience related to independence; it was her experience of “start[ing] working at video store.” Asked what that experience meant to her, she replied, “That, I guess, I am able to be more independent.” When she started working, she said, “I remember being quite happy and proud.” Asked about the
influence this experience had on her life, she said, “I guess, from working there, I now have another part time job but in a different field. I am quite happy about that as well.”

Howard. Howard also selected “work” as the second most important experience of his life. Although his initial response to the question about the reasons for this selection was, “keeping everyone happy,” when asked whether being able to earn his living would also be among the reasons why he considered work important, he replied yes. Moreover, during the interview, Howard spontaneously expressed his pride in both having a job and in being able to save and, with some help from his parents, buy a condominium and move out. He said, “My parents did give me a grant—I should warn you—they did give me a grant. But a lot of the money, I took out of savings.” Indeed, he considered the decision to move out and live independently his most important life decision.

Alan. Alan, who lived his whole life with his parents, made many references to living independently throughout the interview. For him, independence was an important goal for which he was preparing by learning how to cook and clean, as well as how “to take criticism without losing your temper.” To gain work experience and skills, he also worked as a volunteer.

Jimmy and Geoff. Jimmy and Geoff, who first moved away from their parents soon after high school, and who started supporting themselves financially at the same time, did not make much of these events. It is, however, interesting that, as already mentioned, unlike other participants, Jimmy and Geoff—who were unemployed at the time of the interview but who previously held numerous jobs to which they referred as jobs they “could” or were “able to” do—were dissatisfied with their previous jobs because they did not allow them to use their creative abilities and were, for some time, searching for ways to earn their living by doing creative jobs. Accordingly, both Jimmy and Geoff selected “discovering music” as their most, or second most, important life experiences, respectively.

9.3.3.4.2.2 Interpretive Summary
In addition to Pierre, several other participants selected experiences related to moving away from their parents and/or becoming more independent as their important life experiences. However, despite the general similarity of their accounts, participants’ circumstances and emphases were very different in many aspects. For example, like Pierre, Orville also considered moving away from his parents as one of the most significant events of his life. Like Pierre, he also considered breaking away from his parents’ control an important component of his moving-away experience, which interestingly, occurred at the same age as Pierre’s. However, there was one important difference between Pierre and Orville’s accounts of their moving-away experiences. Whereas becoming financially independent from his parents was an important component of Orville’s experience, this was not the case with Pierre, who continued to depend on his parents for financial support after he moved away the first time. Likewise, whereas after several years of (partly) independent living Pierre returned to his parents, Orville continued to live on his own ever since.

Although Mike’s selection of joining the army as his most significant life experience bears some resemblance to Pierre and Orville’s selections in that it also contains moving away from his parents as one of its components, at least in principle, this component was not what was important to Mike. Whereas breaking away from their parents’ control was the key aspect of moving away for Pierre and Orville, the opposite was true for Mike, who considered the army’s higher degree of control—through “tell[ing] you everything,” including what to do and when and how to do it—the most important aspect of his joining-the-army experiences. Likewise, two other important components of Mike’s joining-the-army experiences were financial and social security. None of these components were presents in Pierre and Orville’s accounts. In fact, Orville’s account was the exact opposite: for him, moving away did not only mean financial insecurity but rather a financial crisis, as he had no “funds” and it took him “quite a while to build funds up.”

As for Pierre and Orville, independence was also important to Sarah, Howard, and Alan. For example, Sarah and Howard chose “starting working” (Sarah) and “work” (Howard) as some of their most significant life experiences. For Sarah, starting to work was important because it allowed her to feel more confident in being able to achieve full financial independence and move away from her parents in the near future—which was one of her most important goals. For
Howard, work was important because, at least in part, it allowed him to move away. Likewise, moving away from his parents and living independently are Alan’s most important life goals, for which he was preparing by acquiring a variety of skills necessary for independent living.

On the other hand, 2 participants who either tasted independence earlier or lived independently at the time of the interviews, Jimmy and Geoff, respectively, did not view independence per se as an important life achievement: They never referred to it in terms of accomplishments, but as a routine task anyone could achieve. Instead, they were searching for a particular kind of independence that would allow them to fully enjoy it through the utilization of their creative abilities. Accordingly, their goals were not to find jobs, but to find creative jobs. From this perspective, it is understandable why none of them selected experiences related to moving away and/or living independently (which they did for many years) as important life events. It is also understandable why both Jimmy and Geoff selected “discovering music” as their most or second most important life experiences, respectively. Like them, some other autistic individuals also tied their needs for independence with their needs for the expression of their creativity (e.g., Hadcroft, 2004; McKeen, 1994; Robison, 2008).

Finally, Mike suggested that although he did not know it at the time, he believed that a highly structured army environment was a perfect match for his high need for structure and routines, which is typical for many autistic individuals (APA, 1994). Moreover, he felt that the army also met some, although not all, of his social needs. He appreciated the fact that he was “accepted to some degree,” but most of all he appreciated that he was “taken care of”—“even though you may not be completely socially accepted.” Like Mike, some other autistic individuals found the army to be particularly suited to their need for structure, as well as their social needs. For example, Donna Moon (2005) described her highly positive experience in a two-month-long army training camp as follows:

My time in an army camp provided me with a structured setting where I knew exactly what was expected from me. [. . .] Because of my prolonged depressed moods I was unable, on my own, to enforce any structure in my life and I felt helpless as a result. The army provided a high level of structure that left no time for self-contemplation or reflection. The army also provided a structured social environment. This was something I craved. I found it easier to relate to others when there was a strict social protocol to
follow. [...] I felt a part of the group as we were all going through the same struggle and were working towards the same goal. (p. 341)

However, it should be noted that although Mike found the army to be a perfect match for his need for structure and a somewhat good match for his social needs, he did not believe that the army was overall the perfect match. He said, “Well, it wasn’t a perfect fit, but it, basically, [pause] gave me structure.” Consequently, he also said that knowing what he knows now, he “probably” would not make the same decision again. Likewise, several clinical accounts that mentioned autistic individuals in the army did not always portray the army as a good match for them. For example, Tony W’s army experience was not at all positive because he “got in lots of fights with people. So [he] got [discharged]” (Volkmar & Cohen, 1985, p. 51). Likewise, Wing (1991) described a man who was also discharged because of his motor clumsiness and “inability to do the right thing at the right time” (p. 97).

In summary, like most other autistic adults (e.g., (Grandin, 1995c; Grandin & Barron, 2005; see also Barnard et al., 2001), most participants in this study considered living independently, or partially so, either a source of positive feelings about themselves or an important goal.

9.3.3.4.3 Connecting to the Internet

Pierre identified his connecting to the Internet as his third most important life experience. Importantly, although he previously talked about the “year of correspondence courses” as being one of the most significant times in his life, later in the interview, he changed his mind about its importance and decided that “going online,” 12 years ago, was more important for being the person he is now because it changed his life in several important ways. He said that in addition to spending a lot of time on the Internet reading, he also started to express himself “more” and “about different things” in web forums where he “met an interesting community.” Moreover, it was the Internet that opened a new door for Pierre in finding a way of socializing with people with similar interests—Meetup groups—about which he talked a great deal both in the interview as well as his diaries.
From the third-person perspective, it is also easy to see why Pierre changed his mind about his third most important life experience. First, the Internet decreased Pierre’s social isolation. It allowed him to find the social niche he was longing for—intellectuals (like him) with whom he could exchange ideas without having to make small talk, with which he is extremely uncomfortable. From a motivational psychology perspective, the Internet allowed Pierre to meet his need for belonging (Bargh & McKenna, 2004). As discussed earlier, many other autistic individuals (e.g., Dekker, 1999; McKeen, 1994; Shore, 2001; Tammet, 2006) felt that the Internet allowed them to meet at least some of their social needs (such as get them out of social isolation and/or help them establish relationships). As D. Murray and Lesser (2006) observed,

Exchanging and discovering information of common interest can be a joyful experience, whatever the topic. Connecting with members of one’s interest group over the Internet adds to the general benefits of belonging to a club. Over the internet odd manners, flat intonation or problems keeping up with the pace of social discourse will all be irrelevant. (p. 64)

Because feelings of belonging (i.e., group membership) could influence people’s feelings about themselves (i.e., their self-esteem) in a positive way (Rubin & Hewstone, 1998; Turner, 1985), it is also possible that corresponding on the Internet increased Pierre’s self-esteem. Indeed, such an effect was described in a recent study by Shaw and Gant (2002).

Second, the Internet also allowed Pierre to freely express his ideas, which, perhaps, fulfilled his need for self-expression (Amichai-Hamburger, 2005; McKenna & Seidman, 2006). Moreover, by allowing him to receive social feedback about his thoughts and ideas, the Internet could have also met his need for social recognition (provided the feedback he received was positive or mainly positive). This, in turn, could have also increased Pierre’s self-esteem.

Third, it is possible that Pierre’s experience in online communications could have contributed to his real-life social interactions. As Chris Mitchell (2008) suggested, the Internet opens up opportunities for autistic individuals to develop their social skills in an optimal environment, which can help them feel more confident in real life interactions.

Another benefit of the Internet for Pierre was that it allowed him fast and easy access to information—of any kind. Given his high need for cognition, this is no small benefit. Daniel
Tammet (2006), also with a high need for cognition, wrote how he “was delighted by the sheer wealth of information now available to [him] at the click of a mouse: online encyclopedias, dictionaries, lists of trivia, word and number puzzles—they were all there” (p. 155). Although Pierre did not use the word delighted, it does fit well with his description of the significance of the Internet for his life. Not unimportantly, it is the Internet where Pierre looked for information about autism.

Finally, given all these perceived benefits, and in light of the literature on the effects of the Internet (for a recent review, see Bargh & McKenna, 2004), it is also possible that the Internet has improved Pierre’s overall psychological well-being. From this perspective, Pierre’s change of mind with regard to the importance of connecting to the Internet over taking distance courses becomes easier to understand. Moreover, Pierre’s change of mind also demonstrates that his thinking is not as inflexible as the executive dysfunction hypothesis of autism (Ozonoff, 1995) would suggest. Furthermore, it also suggests that, contrary to the theory of mind deficit hypothesis of autism (Baron-Cohen, 1989b, 1995), Pierre can successfully engage in self-reflection and evaluate the subjective significance of his life experiences.

9.3.3.4.3.1 Other participants: Interpretive Summary

Although no other participant selected experiences associated with the Internet as their important life experiences, as already noted, several participants mentioned that the Internet had a very important role in their lives because it allowed them to socialize with others with similar interests (Mike) or problems (Orville and Geoff). Moreover, like Pierre, all of the other participants except Alan mentioned using Internet for a variety of reasons, such as acquiring information (including information about autism; Mike, Orville, Geoff, Jimmy, and Howard), posting photographs, poems, and essays (Mike, Orville, Geoff, and Jimmy), playing video games (Howard), and socializing (including e-mailing, participating in discussion forums and support groups, and using dating services; all except Alan). From participants’ accounts, it could also be suggested that, as in Pierre’s case, the Internet played an important role in allowing them to fulfill their social needs, as well as their needs for cognition and self-expression, and thus improve their overall psychological well-being. As already discussed, many other autistic
individuals also acknowledged similar benefits of using the Internet (e.g., Dekker, 1999; McKean, 1994; Shore, 2001; Tammet, 2006).

9.3.3.4.3.2 On Other Participants’ Other Significant Life Experiences

In addition to participants’ important life experiences that were similar or related to those of Pierre—reviewed above, which represent most of their experiences—it is also important to mention participants’ other experiences. (For a summary of all most significant life experiences, see Table 10.) Thus, 3 participants selected experiences related to social relationships as their most significant life experiences: being married (Mike), living with his girlfriend (Jimmy), and starting to attend autism support groups (“meeting friends, meeting people, learning how people live with their disabilities”; Howard). A further 3 participants chose experiences related to discovering their hobbies. As already mentioned, for 2 participants it was music: “Discovering music” (Jimmy), and “My parents bought me a transistor radio for Christmas 1970”; Geoff). For Howard, it was “discovering photography.” (It is important to note that Howard initially chose experiences he labeled “school” as the most important, but when asked whether he can narrow it down to some more specific experiences, he selected discovery of photography.) Another 3 participants selected experiences related to their personal development; as already mentioned, 2 participants (Orville and Alan) selected their experience of getting diagnosed with autism, and Alan also chose “reading a book about autism” (which helped him in accepting his diagnosis), whereas Geoff selected “connecting with [cousin] after she dies” (which represented the beginning of his spirituality). Lastly, 2 participants chose experiences related to their achievements: “the production of the map” (Orville) and “getting accepted and starting high school [music academy]” (Sarah).

9.3.3.5 On Turning Points in Pierre’s Life

Pierre identified three events from his life as turning points: skipping a grade, starting university, and moving away from his parents, and starting a PhD program. Two of these experiences, skipping a grade and moving away from home, were already discussed in the preceding section, and about the third, starting university, Pierre did not have much to say other than that it was
significant due to the absence of bullying, which was also already discussed. Therefore, in this section, I make only several general remarks regarding Pierre’s turning-point experiences. Before that, I briefly discuss Pierre’s choice of decision to study history instead of mathematics as a turning point in his life, and his subsequent change of mind about its significance. In the remainder of the section, I discuss the following aspects of Pierre’s turning points: their (a) thematic content; (b) valence; (c) emotionality; (d) specificity, vividness and detail; (e) level of choice; (f) subjective significance; and (g) perceived significance from the third-person perspective

**Switching studies from mathematics to history.** Pierre did not have much to say about switching his studies from mathematics to history (at the graduate level) except that the shift perhaps had an impact on his independence. One way to interpret Pierre’s logic in choosing this event as a turning point is that it was a significant shift in his academic life at the time and that the shift was based on his decision. In other words, the switch could have given him a feeling of independence at the time. However, it is also understandable that from the current perspective, Pierre does not see that this event, or the feeling of independence he might have felt at the time, made his life much different than it was before, or that he changed as a person as a result of this switch.

**Thematic content.** Two of Pierre’s turning points—starting university and moving away from his parents and starting a PhD program—are typical “transition-linked turning points” (Graber & Brooks Gunn, 1996). Leaving home, and independent living, is considered normative, age-graded, role transition in Western societies (Havighurst, 1948; Levinson, 1986) and is commonly found among turning points of typical adults (Rönkä, Orava, & Pulkkinen, 2003). However, although starting university is a normative transition, Pierre’s reason for labeling this point as turning (i.e., absence of bullying) is not typical.

On the other hand, although skipping a grade is a transition event, it is not among culturally expected, normative, events and is, therefore, usually not included among the turning points of typical adults; such events usually get summed up under the category of “other” and described as “unique experiences not relating to normative, age-graded transitions” (Rönkä et al., 2003, p. 211). However, such events are sometimes mentioned in case studies of people who skipped grades and found it to be a “mistake” (e.g., Joseph Kid, described by White, 1966). Furthermore,
when the traumatic nature of Pierre’s grade skipping is taken into account, we find that such experiences often do attain turning point status in the lives of people who experienced trauma (Berntsen & Rubin, 2007).

**Valence.** Two of Pierre’s turning points were positive, and one—skipping a grade—negative. Given the nature of these experiences, such distribution of valence would be expected in typical population: culturally expected transitions in the life course are known to be biased towards positive events, while trauma experiences are, by definition, negative (Berntsen & Rubin, 2004). However, as previously mentioned, autistic people usually find transitions difficult (Attwood, 2006; Grandin, 1995c); sometimes they can reach proportions of developmental crises (Tantam, 2000a). Therefore, it should not be taken for granted that Pierre’s transition to temporary and partly independent living was positive.

**Emotionality.** Only one of Pierre’s turning points seemed to be associated with *emotional memories*. For example, Pierre was very specific with regard to his remembered emotions (i.e., anger) and emotional reactions (crying) associated with events related to skipping a grade, which is consistent with the literature on significant life memories (termed “personal event memories” and “self-defining memories”; Pillemer, 1998, 2001; J. A. Singer & Salovey, 1993, respectively). Moreover, as already described, and consistent with the literature on traumatic memories (Brewin et al., 1996; Ehlers & Clark, 2000), Pierre’s memories of these events also evoked intense emotional reaction (i.e., anger). On the other hand, Pierre did not describe any specific emotions with regard to his other—positive—turning points, and his emotional expressions while talking about them were rather moderate. The difference in the emotionality of Pierre’s turning points could be related to research findings that memories of positive events feel less emotional than memories of negative events (Bohanek, Fivush, & Walker, 2005). It could also be related to the evidence that suggests that more specific memories are more emotional (Christianson & Safer, 1996); as will be discussed in the next section, Pierre’s memories of his negative experiences were also more specific than his memories of positive ones.

**Specificity, vividness, and detail.** Pierre’s memories related to skipping a grade were the most *specific, vivid, and detailed*. For example, Pierre remembered the names of his classmates who bullied him, what they said and how they said it, what they did when the incidents happened,
how he felt and what he thought, and how his parents reacted. In the case of teacher bullying, he remembered the specific question asked, his answer, the teacher’s response, as well as his and his parents’ reactions. Such a level of vividness is in accordance with the literature on important memories such as self-defining memories (J. A. Singer & Salovey, 1993) and traumatic memories (Brewin, et al., 1996; Ehlers & Clark, 2000).

On the other hand, memories of Pierre’s other turning points were more general. For example, his memories of starting a PhD program involved summaries of repeated events from the specified time period. Such memories, termed by Conway (1996; Conway & Pleydell-Pearce, 2000) “lifetime periods,” are nonspecific and consist of thematically grouped memories of the period. Although such general memories are commonly reported when people are asked about specific important autobiographical memories (Pillemer, Picariello, Law, & Reichman, 1996; J. A. Singer & Moffitt, 1991–1992), the issue of specificity and generality of autobiographical memory is particularly relevant in autism because there is empirical evidence that suggests that autistic individuals have particular difficulties with remembering specific events from their past (Crane & Goddard, 2008). Not unimportantly, the research also shows increased generality in autobiographical memories—positive ones in particular—of depressed and traumatized persons (Moffitt, Singer, Nelligan, Carlson, & Vyse, 1994; J. M.G. Williams et al., 2007; J. M. G. Williams & Broadbent, 1986).

However, clinical (Attwood, 1998, 2006), case (Cesaroni & Garber, 1991), biographical (Cutler, 2004) and autobiographical evidence (Gerland, 1997; Grandin, 1995c; Grandin & Scariano, 1986; Fleisher, 2003; Peers, 2003; Prince-Hughes, 2004; D. Williams, 1992) suggests that autistic individuals have an outstanding autobiographical memory. For example, Marc Fleisher (2003) seems to have a very vivid and detailed memory of his school years:

I can remember many other things about what happened to me socially in my school years—the things people said, many of their names, even the licence plate on one of their cars, will be deep in my memory and will remain there always. When and if I get to 70, when most of these people will have forgotten I even existed, I will still remember every single detail as accurately as if it were yesterday. (p. 41)

Similarly, Dawn Prince-Hughes (2004) wrote,
When I close my eyes, I can play it back like a three-dimensional tape, replete with the smells, the sensations, and my feelings about it. I have always had this photographic or eidetic memory, and all of my many recollections of the past have a quality that makes them seem almost more real than the present. (p. 16)

Moreover, Dawn’s (Prince-Hughes, 2004) vivid descriptions of many childhood events testify to the validity of her claim. For example, her account of one incident with her third-grade math teacher involves descriptions of the location of the incident; the teacher’s emotions, actions, words, and appearance; and her own actions (or rather their absence), words, emotional reactions and feelings, thoughts, and sensory perceptions:

Once she [teacher] sent me out in the hall after becoming disgusted with me for not being able to complete a multiplication table. She screamed in my face, “Do that table!” I couldn’t move. When she came back some minutes later, I was still in exactly the same position. She put her face three inches from mine (I still remember a tiny triangular scar she had on her forehead) and screamed the same sentence again, “Do that table!” I was literally petrified.

When she returned yet again a long time later to find me in the same position, she screamed, “Do that table, or I’m calling your mother!” I broke down and sobbed, without moving. “Call my mother, please. I want my mother.” She leaned back, arms folded across her chest, and informed me that she would do no such thing. My mind swam. . . . Now the threatening and disembodied pieces of my teacher swirled around me, attacking from every angle. I was caught in a whirlwind of horrible sensory information and unrelenting criticism. I needed my mother and knew that this demon, in the form of flying, taunting parts, had the power to keep her from me. (pp. 42–3)

Temple Grandin (Grandin & Scariano, 1986) also vividly recalled a school bullying incident that got her expelled from school. Her account includes names, descriptions of locations, objects, people, what they said, their facial expressions, as well as her own actions, thoughts, and feelings:

Kids teased me and I reacted by smacking them. I’d been warned that such conduct was not acceptable. Still, when Mary Lurie, a girl in my grade, passed me in the hallway on the way to music class, she turned and looked at me. Lifting her nose in the air and curling her lips in a sneer, she spat, “Retard! You’re nothing but a retard!”

Anger, hot and quick, ripped through me. I was carrying my history book. Without hesitation I threw my arm back and then forward. My history book zoomed through the air like a guided missile and hit Mary in the eye. She screamed and I walked away, not even bothering to pick up my history book.

That night at home the phone rang and I answered. It was Mr. Harlow, the principal of Cherry Hill Girls School. He didn’t even ask to speak to one of my parents. He just said, “Don’t bother coming back to school. You are incorrigible. Mrs. Lurie is
very upset. You could have blinded Mary and all because of your nasty, uncontrollable temper.”

I hung up the phone. Anger and frustration surged through me and I trembled, sick at my stomach. Mr. Harlow hadn’t even asked to hear my side of it. He just assumed that since I was “different” I was entirely to blame. (pp. 59–61)

Grandin Temple (Grandin & Scariano, 1986) continued her account of the incident with equally detailed and vivid descriptions of subsequent conversations with her parents. Importantly, her mother corroborated Temple’s descriptions of this and other events in her own autobiography (Cutler, 2004). Likewise, the parents of one of the participants in Cesaroni and Garber’s (1991) study also confirmed the validity of their son’s early memories, thus suggesting that at least some autistic individuals have vivid and detailed—if not exceptionally so—autobiographical memories of at least some of their important life events as Pierre seems to have (at least for his negative life events).

**Level of choice.** Two of Pierre’s turning points came about through *his choices*, which is comparable to the finding on turning points of typical adults (Rönkä et al., 2003). Pierre’s almost complete lack of choice and agency in (later phases of) his skipping-a-grade turning point, is also consistent with experiences of other people who were bullied and were, as a result, “changed . . . profoundly” (J. S. Peterson & Ray, 2006a, p. 260). As already mentioned, a sense of helplessness (as illustrated in Pierre’s remark “there was nothing I could do”) is common among chronically bullied individuals (Borg, 1998; Craig et al., 2007; J. S. Peterson & Ray, 2006a).

One way to explain the difference in choice and agency among Pierre’s turning points is to consider their complexity. For example, his starting a PhD program involved choosing between two or more options about which he had all of the necessary information. On the other hand, dealing with the consequences of skipping a grade (i.e., bullying), required knowledge, maturity and support that Pierre did not have. The list of unsuccessful strategies Pierre used in his attempts to deal with his bullies seems to support this interpretation; he tried telling, ignoring, crying, aggression, and skipping school, and after exhausting the choices he knew about, “there was nothing [else he] could do.” Importantly, it is this nonagentive turn in his life that Pierre recognized as a turning point.
**Subjective significance.** Subjective significance of Pierre’s turning points was related to his feelings about himself. On the one hand, skipping a grade marked the beginning of his feeling of helplessness: after skipping a grade, Pierre said, he felt that he could not cope with the world’s challenges as well as before. On the other hand, the significance of starting university and his PhD program was that these transitions allowed him to feel better about himself and about his ability to adapt to new environments and pursue and enjoy new experiences.

**Perceived significance from the third-person perspective.** From a third-person perspective, Pierre’s personal discontinuity, both short- and long-term, after skipping a grade is obvious. There is no doubt that Pierre was not the same person after as he was before skipping a grade. Before, he was full of action; after, he was helpless. Before, he was self-confident; after, he was unsure of himself. (Pierre said that “at first” he believed that others were “the problem,” thus implicitly expressing his belief that before he skipped the grade, he saw himself as being “okay” [i.e., “not a problem”]. In other words, one could take this to mean that after he skipped the grade, Pierre started seeing himself as “a problem,” or, at least, that his view of himself was not as positive as before.) Before, his hopes were high; after, he hoped the bullies would not come to school or would not see him. Before, Pierre looked forward to going to school and learning; after, he was preoccupied with avoiding bullying. Before, we can imagine him hoping to have enjoyable social experiences; after, we can see him avoiding social contacts altogether. Before, the world was good; after, he did not know any more.

On the other hand, although short-term personal discontinuities in Pierre’s other turning points were also obvious even from a third-person perspective, this was not so with regard to their long-term effects. Thus, although it is easy to see how not having to worry about bullying any more after starting university made Pierre feel differently both about himself and the world, the long-term effects of this change are not so obvious. Likewise, although it is obvious that a temporary change in Pierre’s lifestyle during his PhD studies made him feel more independent than before, this change must have been erased once he returned home. Therefore, although Pierre’s experiences were new and his feeling of independence was important for his self-esteem at the time, it is not obvious if these temporary changes had any lasting effect on Pierre’s self-esteem or on him as a person.
9.3.3.5.1 Turning Points in Lives of Other Participants: Interpretive Summary

Half of the participants identified at least one turning point in their lives. However, 3 participants (Sarah, Alan, and Howard) did not consider any events from their lives dramatic enough to deserve to be labeled turning points. Two participants (Orville and Geoff) chose more than one turning point (2 and 4, respectively). Only 2 out of 8 turning points (both selected by Geoff) were identical with the most significant life events selected by the same participant.

**Thematic content.** Turning points of 2 participants were related to social relationships, Mike and Geoff’s: “My partner wants to be more . . . just friends” and “Falling in love for the first time, and being jolted out of the emotional shut-down,” respectively. A further 2, both selected by Geoff, were related to personal development: “when [a cousin] dies, and I connect with her” (which refers to the same experience Geoff previously described as the most significant experience of his life); and “starting to get involved with Buddhism and meditating.” Two participants, Orville and Geoff, also chose turning points related to the discovery of a field of interest, one leading to a future occupation (“My older brother gave me [a book] called the American Electricians’ Handbook,” with which Orville educated himself to become an electrician); and the other, to the hobby—music—which Geoff also previously described as one of his most significant life experiences (“Getting the radio and hearing the music, that’s turning point number one.”) (It is interesting to note that although Geoff, like Pierre, gave two of his life experiences statuses as both turning points and most significant life events, he ranked their significance differently within their chosen categories. Thus, whereas he selected the discovery of music as a “turning point number one,” he chose his spiritual awaking as his most significant life experience.) One participant (Orville) also selected an event related to achievement, or rather, thwarted efforts to that end: “I’ve been suspended from college [for] no purpose or anything and that [. . .] felt [. . .] like the carpet had been pulled from underneath my feet.” Finally, 1 participant (Jimmy) chose his work-related experiences as a turning point: “When I took that job in [Ottawa] [. . .] [it] gave me more confidence.”

It is interesting that, unlike Pierre, whose two turning points were related to normative transitions, none of the other participants chose such experiences. Instead, they selected more
idiosyncratic experiences such as sudden changes in marital relations or in student status, and discovering new aspects of the world after getting a book or radio, or learning about Buddhism.

**Emotional content.** As in Pierre’s case, most turning points of other participants were positive: 6 out of 8. Two participants, Mike and Orville, who selected negatively valenced events, changes in marital relations and suspension from college, expressed—at least indirectly—similar feelings about their chosen turning points, which are consistent with confusion and disappointment. However, whereas there was no noticeable change in Orville’s voice, facial expressions, or gestures during his description of the events associated with his turning-point experiences, Mike’s nonverbal expressions were consistent with his story: His voice was noticeably different (the tempo was slower, the tone was lower, and there was an overtone of sadness and loss), and his hand movements (hand dropping) increased, all of which were consistent with disappointment, sadness, and sense of loss. Indeed, when specifically asked about his most disappointing life experience, Mike replied, “Marriage not going the way it used to go.”

However, it is important to note that none of these 2 participants were able to label their emotions associated with these memories. Thus, when asked how they felt when the events they described happened, in both cases it looked as if the participants did not hear the question and instead proceeded to give more factual details. It is also interesting that both participants replied by using the dialog that occurred immediately after they heard “bad news,” perhaps suggesting that the words they said at the time were the answers to the question about how they felt. For example, when Orville was asked, “How did you feel [when he was told that he was suspended]?” he replied, “And I even asked, ‘Well, what about hearing?’” and immediately vice principal just [said], raising voice, ‘No, there’s no hearing involved. You’re suspended effective immediately’ is what he said.” Likewise, when asked about his feelings at the time, Mike replied, “I said, ‘I can’t help it.’ She [his wife] goes, ‘I can’t either.’” Nevertheless, both of these answers are clearly consistent with a state of confusion, as their other remarks also indicate. For example, Orville said that he was suspended for “no purpose,” and Mike said, “I don’t know the reason why . . . I don’t understand.”

With regard to positive experiences, only 1 participant (Geoff) named two of his emotions (love and joy) associated with two of his turning-point experiences (falling in love for the first time
and discovering music, respectively). Although another participant (Jimmy) attempted to refer to his feelings at the time saying, “I felt a little different [. . .] I felt a little better about that [. . .] just kinda felt [that] it gave me more confidence there,” other participants did not make specific references to their feelings when talking about their turning points. Finally, only Geoff accompanied the description of one of his four turning points (discovery of music) with both facial expressions and changing his voice, both of which reflected the joy and excitement of the described moment.

**Specificity, vividness, and detail.** The participants’ accounts differed with respect to the levels of specificity and vividness. All except one account were very specific and referred to a particular event (e.g., getting a specific book or radio). However, Mike’s account referred to his whole experience associated with his partner’s change of feelings towards him and included events that stretched over several years. Although the participants’ accounts differed in the level of detail they contained, all accounts contained a fair amount of descriptions of places, objects, interactions with people, and elements of conversations, as well as the descriptions of their lives before the turning points so that the contrast with their lives after the turning points was obvious.

**Level of choice.** Only 2 out of 8 turning points happened as a result of participants’ choices: Jimmy’s decision to take a particular job and Geoff’s decision to start learning about Buddhism and meditating. In all other instances, either someone else initiated the events that became turning points, or, in the case of falling in love, the event unfolded without the participant making a conscious choice about it.

**Subjective significance.** The perceived significances of the participants’ turning points could be grouped into two broad categories: (a) **self-discovery** and (b) the change in the planned or expected course of life.

(a) Most turning points (6) belonged to the **self-discovery** group. Three turning points were related to the **discovery of participants’ unknown abilities, talents or affinities**. One was Orville’s discovery of the handbook for electricians, from which he educated himself to become an electrician and consequently change his area of work. He described the significance of this event as follows:
Before then, it was all into maps and survey work, and geography, is what I was into, but I seemed to turn from maps in a sense of geography into charts in the sense of electrical flow charts, there, into basic electrical circuits, is what that turning point seemed to be.

The second turning point from this category was Geoff’s discovery of music, which he described in the following way:

I think it led to, you know, a few years later, me getting in touch with my own creativity, becoming a musician myself. [long pause] And, I think, music also opened me up to, [long pause] sort of, a whole world of emotions and spirituality in a way that I would not have access to otherwise. It was like it was able to get through to me on a level that nothing else could.

The third turning point was selected by Jimmy, who, after starting working at the job he termed a turning point, discovered that he can “learn [his] way around the [big] city [. . .]—[which] was drastically different than anything [he has] ever done.” This, together with some other aspects of that job made him “[feel] better” about himself including giving him “more confidence.” Geoff’s discovery of a new emotion—love—when he fell in love for the first time, as well as his two other discoveries related to his spirituality (connecting with a dead cousin and discovering Buddhism), also belong to this category.

(b) Two turning points drew their significance from the change in the expected or planned course of life: Mike’s change in spousal relations—from lovers to friends—and Orville’s suspension from college, which meant that “instead of being able to go on to education that [he was] planning and getting a better job and better income and all the rest of it, [. . .] [he] almost gone the other way over.”

**Significance from the third-person perspective.** Given their entire accounts, 2 participants, Howard and Mike, omitted to select some events that from the third-person perspective seemed to qualify for the turning point label. For example, although Howard did not consider any of his life experiences dramatic enough to deserve being labeled turning points, his moving away from his parents into his own condo—about which he proudly talked several times during the interview—seemed an obvious candidate for such a label. However, when confronted with this seeming omission by being reminded of the event in question: “How about when you moved out,
did that feel like a . . .?” Howard replied, “Yeah, I guess so, but I wanted to move out for a long
time, so it was a dream come true.” Therefore, his original negative answer seems to be justified
in the sense that because he planned and expected this change in life, it was not a “dramatic
change” as the question stipulated. So from this perspective, it is clear that because Howard’s
life did not really change a previously expected course of life, he did not consider it a turning
point.

From this perspective then, Mike’s presupposed “omission” in labeling his two self-defining
memories, joining the army and marrying—which were his two most important life decisions—as turning points also becomes reasonable. That is, Mike planned both of these events, and thus,
they did not change the course of his planned life, which was not the case with his wife’s sudden
decision to be “just friends.”

9.3.3.6 On Pierre’s Most Important Decisions

Pierre’s most important life decisions were changing the direction of his studies at the graduate
level (switching from mathematics to history) and choosing a particular university for his PhD
studies. Pierre is still happy with the former decision while he regrets the latter.

Despite giving them such high status (as “most significant”), Pierre did not have much to say
about the importance of these decisions in regard to the course of his life: he said that the
decision to switch to history was important because he likes the subject and that the choice of
university was important because he was constantly having conflicts with his supervisor and felt
helpless. Therefore, the importance of these decisions seemed to lie not in their long-term
consequences but in their impact on his short-term life satisfaction or dissatisfaction.

From a third-person perspective, it is interesting that both of Pierre’s important decisions were
related to his education and that they were both made in his adulthood. This could have some

24 The question was, “Can you tell me about some experiences or events after which your life changed so
dramatically that it felt like a different life from that point on?”
bearing on understanding Pierre’s current difficulties with decision making (as discussed above). For example, these choices may suggest that Pierre did not make many decisions throughout his life that had influence on its course, and second, that decisions he did make were within one area—the area of his expertise, knowledge acquisition.

Pierre’s decision to switch his field of study is particularly interesting when taking into account the traditional view of autism according to which autistic individuals have a preference for the status quo (APA, 1994; Attwood, 2006; Kanner, 1943). Moreover, according to one influential theory of autism (the executive dysfunction hypothesis; Ozonoff, 1995), cognitive inflexibility (one of the main aspects of executive functioning) is central to autism. Indeed, the cognitive inflexibility of autistic individuals—including their difficulties with complex decision making (Goldstein, Johnson, & Minshew, 2001)—is well documented by research (for a recent review, see Hill, 2004). However, as already reviewed, all evidence in support of the executive dysfunction hypothesis comes from autistic individuals’ performance on neuropsychological tests and experimental tasks (Hill, 2004) and not from real life. Because Pierre’s decision to switch his field of study involved more than just choosing between two or more options (it also required disengagement from the previously chosen academic domain), it could be argued that complex decision making in real life perhaps depends on context, motivation, and availability of information. Thus, although Pierre seemed to have difficulties with decision making in the context of employment, low motivation, and little information, he did not appear to have such problems in the context of education, high motivation, and plentiful information.

It is also interesting that although Pierre suggested that he did not think much about decisions he could have made (“the roads not taken”), he did say that if given another chance, he would develop his singing and acting talents, which is in line with his current continuing education and volunteer engagements. One of the Pierre’s remarks—although made in another context (i.e., about important life lessons, to be discussed next)—about the importance of making one’s own decisions and not following others’, is also important to mention because it raises the question about Pierre’s involvement in the decisions regarding his education. This may be an important issue for autistic individuals because some other autistic adults reported that many decisions are made for them by their parents and teachers (e.g., C. Mitchell, 2005).
9.3.3.6.1 Other Participants

Sarah. Like Pierre’s, Sarah’s most important life decision was also related to education, and it also involved a major switch: in her case, from music to library science, which she made after high school. She explained: “I didn’t wanna to get really serious with music as a career [. . .] [However, I] still wanted to continue to sing, but more as, like, a fun, hobby, rather than as a career.” As already noted, Sarah continued to sing as an armature and felt that she “made the right decision.” She also said,

[High school experience] made me change my career cause I was going to go into music when I was quite young, like, when I was a little kid, I always wanted to be a singer and stuff. After I attended this school, I realized that it was a lot more work, a lot more time.

Geoff. Like for Pierre and Sarah, one of Geoff’s most important decisions, the first one he selected, was also related to education, and more specifically, to switching his field of study, in his case from engineering to sociology during his undergraduate studies.

Important life decisions. [long pause] Well, one I can think of, really, is in my second year of university—switching from engineering to sociology. Only because [long pause], you know, not necessarily because I got into sociology or . . . but the importance of the decision was . . . I think, I had—and maybe this is something to do with autism—I had this, sort of, thing in my head where if I decided to do something, I had to see it through until it finished. I couldn’t . . . and that was, really, the first time I had ever, in the middle of something, said, No, I can’t go on with this. I can’t continue, and realize that it was okay, and it was even valid, and a good thing to say, No, I can’t do this, this is not right for me, I should not do this anymore, I’m gonna stop, and I’m going to go over here and do that. And that was the first time I’ve ever done it. And it was really hard. And I . . . [long pause] and I know I can say how hard it was because it took me a year and, I think, two months into the second year, whereas really if I have been self-aware, I should’ve known this within the two weeks of the first year. But I didn’t. So in that sense it was important. It was the first time I realized that I could change direction if something wasn’t working out. I didn’t have to see it right through till the end no matter what.

Geoff’s two other important decisions were to pursue his spirituality and “to quit [his] job, and take a trip across Canada, and write a book”—both of which I previously described. Like Sarah, he also felt that the decisions he made were the right ones.
**Jimmy.** As already mentioned, Jimmy’s most important decision also involved education, and it also involved a “switch.” However, his switch was twofold as it involved not only a change in the field of interest, from restaurant management to graphic design, but also from working to being a student. He said that because he “always hated” his jobs—which did not fit his abilities and which he only took because they were “available”—when he was thirty-eight, he “decided to go and try and take a course, and try to get into something completely different.” When asked to say more about his decision, Jimmy said, “Well, I just knew that I would never be happy doing that, I didn’t have a future in it, and wasn’t going to be successful in it, so . . . [thought left unfinished]. He was also happy with the decision he made.

**Mike.** One of Mike’s two most important life decisions, joining the army, was also related to his education although it also included elements of employment. However, unlike Sarah, Geoff, and Jimmy, if Mike had the opportunity to live his life again, he would “probably not” make the same decision again. Although he believed that the army helped him in many ways (“Well, it wasn’t a perfect fit, but it, basically, [pause] gave me structure”), he said that, knowing what he knows now, he “probably would’ve went into high-tech electronics or computers with a private company or something.”

Mike’s second most important decision was to get married. Although his initial evaluation of this decision was positive (“It was a good decision back . . . even now. You know, life’s not perfect.”), when asked if, knowing then what he knows now, he would make the same decision again, he replied,

> Probably not. I may have . . . I may have, actually, just . . . remained single [in a very low voice]. Yeah, I think I would’ve remained single, but, maybe, just had [lifts his hand from the table and drops it back making a sound] a girlfriend [the same movement and sound], or girlfriends [the same movement and sound], hmm, but I probably would not have married.

**Howard.** One of Howard’s most important life decisions was also related to education, or, more specifically, going to college. However, his most important life decision was to move out when he was thirty-four. When asked about his important decisions, he replied: “To go to work and go to college . . . to move out, that’s the most important, to move out.” He said that moving out was the most important because “I like to live on my own.” He was happy with all three decisions he
mentioned and would make the same decisions again if he had the opportunity to live his life again.

**Orville.** As already discussed, Orville’s most important decision was related to obtaining the diagnosis of autism, or as he put it “to search[ing] for an answer” for his social problems. In fact, his second most important decision, to change his place of residence when he was forty-seven, was also indirectly related to the same search; however, that decision had several other aspects, main of which was, as for the other participants, related to education. He described his decision as follows:

It’s decision to leave my place when I was living south of [Newmarket], and this was during the early 90s when there was a recession and work fell down, to pursue the further education in [Ottawa] where I was for and apply and be accepted, and all that, through there, and then be able to pursue this other search even more that lead to this diagnosis, whereas if I stayed where I was, south of [Newmarket], I don’t think someone telling me . . . I just wouldn’t have found any more answers than what I’d got [. . .] from earliest years right up till 1992 when I lived in that area.

When asked to say more about the importance of this decision for his pursuit of further education, he replied:

Well, I had been searching before that in the 1980s by taking courses both through college and through university extension courses to pursue different areas of concern, and when I found this transportation engineering technology course open at the college down here, I felt that that would be [of] key interest because I would be concerned with transportation maps, and everything like that, trains, and so on, and that would be, more or less, down my line, and that’s how the education part of it came into being . . . and it was, like I said, it wasn’t too far away from where I lived. [. . .] And it’d just give me different experience along with means of pursuing this search, which was more in the background in my mind—it wasn’t the reason I really moved down here, [it] was something I, sort of, took up after moving here—but the main purpose of moving here was to pursue this transportation engineering.

Moreover, Orville considered this change important for another reason—it provided him with new experiences:

And also getting a different, I would say, life experience as far as geographical background because I’d spent all my life in that area [and] practically got to know every street, every road, everything, so much, and it got [to the] point where I am just yawning, almost looking for some new venues, something over the hill. And by moving . . . it
wasn’t very far, [it] wasn’t like to Vancouver or anything like [that, it] still gave me fresh geographical face to look at, new surroundings, as people say, “The change is as good as the rest.”

When reflecting on the influence of this decision on his life, Orville said, “[It] just led to a whole series of events that this started. This is like the catalyst that started the events.” He believed that if he did not choose to move, his life “would be just the same way it was before then, just no change, live in the same place, same boredom, same surroundings, as though my life would just be going downhill with no new experiences at all.”

Alan. Like the other participants’ decisions, Alan’s most important decisions were also related to learning, although not the formal kind as was the case with other participants; rather his decisions were about learning how to live independently. Alan’s account was also unique in several other respects. For example, he was the only participant who had some difficulties remembering his important life decisions and the only participant who acknowledged that his parents make decisions for him. Here is the relevant portion of our exchange about this issue:

L: What is the most important decision you have made in your life?
A: Okay. I don’t know. I don’t know what it is.
L: Did you make any decisions?
A: Okay. Oh, I see. Okay. No, not really.
L: Not really.
A: No.
L: So who is making decisions for you?
A: My parents usually make decisions for me, okay. I know one important decision for my life was trying to learn how to cook things and how to [do other] things from life when my parents are not around anymore, that’s right.
L: So you decided that you are going to learn that, right?
A: That’s right; learn that, that’s right.
L: How old were you when you decided this?
A: I was about 28, 29 years old.
L: And if you didn’t choose to learn how to cook, how would your life be different now?
A: Well, I would [be] eating out a lot, you know, [and] eating so much.
[. . .]
L: Okay. And have you made any other decisions that you consider important?
A: Okay. Yes, trying to know . . . trying to not spend so much money on things which I don’t need or just try to use money sparingly or other things, or try to work, things . . . and have a good job as well.
L: Uh-huh. How old were you when you made a decision to try not to spend your money on things you don’t need?
A: 30. That was the last year, or two years ago, actually.
L: Okay. And how would your life be different if you didn’t make this decision?
A: I don’t know.
L: Would it be any different?
A: Yes, it would be much different.
L: How?
A: I wouldn’t know what to do with it, I would be screwed, basically.
L: Okay. And how do you feel now about making this decision?
A: I feel that it’s very important, it’s critical, there.

9.3.3.6.2 Interpretive Summary

As for Pierre, all other participants’ most important decisions were also related to education, either formal or informal. It is interesting that, as for Pierre, changing the area of study was also the most important decision for 2 other participants, Sarah and Geoff, although they made their decisions at different levels of education than Pierre did—high school and undergraduate studies, respectively. Although the decisions of most participants were related to formal education, 2 participants’ decisions were associated with informal learning involving gaining necessary skills for independent living, such as cooking and managing money (Alan), and searching for answers about social difficulties through reading and talking to others (Orville). Most of the important decisions of the 3 other participants contained both education and work components: joining the army (Mike) and continuing education instead of looking for work (Jimmy and Orville). Two other participants, Howard and Geoff, also mentioned their work-related decisions (starting and quitting, respectively). Other important decisions of this study’s participants were related to moving (moving out and moving from one town to another, in Howard and Orville’s cases, respectively); interpersonal relationships (getting married; Mike), and taking a trip and writing a book (Geoff).

Like for the participants in this study, educational decisions were also important to other autistic individuals; they included decisions regarding choosing a particular field of study (e.g., Grandin & Scariano, 1986; C. Mitchell, 2005) or switching it (e.g., Shore, 2001), and going back to school (e.g., Lawson, 2000; Prince-Hughes, 2004). Likewise, as already discussed, decisions about informal learning, regarding their social difficulties in particular, were also commonly
found in autistic individuals’ autobiographical accounts (e.g., Dumortier, 2004; Gerland, 1997; Grandin & Scariano, 1986; Williams, 1992).

All of the participants in this study were able to provide at least one important decision that they made as well as to support their selections with appropriate justifications in regard to their importance. However, it should be noted that 1 participant (Alan) had some initial difficulties remembering his important life decisions. Moreover, Alan was also the only participant who acknowledged that his parents usually make important decisions for him, which, at least in part, explains why he initially said that he did not make any important decisions in his life. Although Alan’s relative lack of engagement in decision making could be viewed as being consistent with the executive dysfunction hypothesis (Ozonoff, 1995), as well as research evidence suggesting that autistic individuals have a specific difficulty with decision making (Goldstein et al., 2001), no other participant in this study seemed to have such difficulties. To the contrary, most other participants seemed to have used the relevant information to guide their decision making processes at crucial moments in their lives. Geoff provided a particularly good example of decision making when he described how despite his tendency to finish everything he starts, once he realized that engineering was not what he expected, he was able to make an appropriate decision and change his field of study (although he felt that it took him too long to do it). Indeed, such ability is a good illustration of cognitive flexibility, which is considered to be lacking in autistic individuals (Goldstein et al., 2001; Hill, 2004). Thus, as in Pierre’s case, accounts of other participants suggest that real life decision making of autistic—as well as non-autistic—individuals may crucially depend on motivation, which is a component that is usually absent in laboratory studies.

It is also interesting that whereas some recent studies have also provided evidence that decision making of autistic individuals is not informed by emotional context (De Martino, Harrison, Knafo, Bird, & Dolan, 2008), the reports of the participants in this study suggested the opposite to be true. Thus, most participants either explicitly or implicitly reported making their decisions based on their dissatisfaction with relevant aspects of their lives, which they wished to change. Indeed, it is their feelings that seemed to be the guides for their decision making. As Jimmy put it, it was his feeling of unhappiness with his job that led him to the decision to try to upgrade his qualifications so that he can pursue a job that suits his talents.
Finally, it is also interesting that most participants (all except Pierre regarding one of his 
decisions, a choice of a particular university, and Mike regarding both of his most significant 
decisions, to join the army and to get married) considered their most important decisions to be 
the right decisions. Moreover, considering the information available to these 2 participants at the 
time they made their decisions, it becomes obvious that the reasons why their decisions did not 
lead to the expected results were unrelated to either their emotional or cognitive characteristics. 
Therefore, taken together, this study’s participants’ reports about their decision making could be 
viewed as adding to other autistic individuals’ claims about their relatively good decision making 
abilities (e.g., Grandin & Barron, 2005; Grandin & Scariano, 1986; Kolinski, 1995; Tammet, 
2006).

9.3.3.7 On Pierre’s Learning from Experience

The most important inference Pierre made from his experience is that “it is important to try to 
make your own decisions—to not let other people make decisions for you.” Although, when 
specifically asked about it, he was not able (or not prepared)\(^\text{25}\) to remember a specific event or 
events from which he deduced this lesson, he did mention during the interview that he did not 
like some of the decisions his family members made for him, such as a decision to take distance 
courses and decisions that ultimately led to his peers and teachers bullying him.

Although it is clear that Pierre strongly believed in the importance of making one’s own 
decisions, it is less clear from the interview (and diary) evidence how much he practices this. 
Nevertheless, Pierre’s insight is important because it shows that he was able to successfully 
engage in the process of self-reflection and, through it, gain important conclusions relevant for 
his future—a process thought to be outside of autistic individuals’ abilities (Baron-Cohen, 
1989b; Powell & Jordan, 1993; Sacks, 1995). Given such a perspective on autistic individuals’ 
abilities, it is not surprising that there are no studies that explore autistic individuals’

\(^{25}\) It is important to note that, the first time he was asked this question, he seemed to have remembered some very 
unpleasant events. This was evident because he said that he did not feel like talking about it at the moment. 
However, when asked the same question on another occasion, he simply said that he could not remember any 
specific events.
autobiographical reasoning—making connections among and between memories and the present (T. Habermas & Bluck, 2000; McLean & Thorne, 2003; Pasupathi & Mansour, 2006; Thorne, McLean, & Lawrence, 2004), as well as the future. However, autobiographical evidence is replete with examples of autistic individuals’ autobiographical reasoning. For example, Liane Holliday Willey (2001) described “the lesson” she learned from an incident with her employer in which she was taken advantage of and concluded:

It made me look at others who hold positions of authority and prestige through suspicious lenses. Are they who they say they are, I always ask myself? Will they lead me astray, I wonder? Help me figure this one out, I ask my husband or my family. (p. 47)

Moreover, Liane also described a strategy she uses to aid her autobiographical reasoning in difficult situations:

When I write or even draw an image of my confusion, I am more likely than not to tap into the part of my mind that holds a similar set of situations I have already lived through to tell about. Writing and drawing things helps me to access my memory banks and more. When my issues are visually laid out before me, I can usually find a way to apply logic and intelligence to the situation. It’s as if the problem, once put on paper, stands as something I can be objective about and therefore somewhat removed from, so that I am then able to look at the situation without the layers of frustration and hurt attached to it. Once a safe distance away, I can slowly begin a process of self-questioning. I can slowly solve the mystery. (p. 31)

9.3.3.7.1 Other Participants

All but one participant (Howard) was able to think of at least one important life lesson. Like Pierre, 4 other participants’ lessons involved gaining personal knowledge: Mike said that his army experience taught him “the value of work: you have to work hard to achieve.” When Sarah completed what she described as a “difficult [college] program,” she said she learned the importance of being persistent: “you should never give up on achieving your goals and dreams.” Likewise, Alan’s unsuccessful efforts to keep things the same taught him that “we have to accept change, no matter how difficult it is.” Finally, by “liv[ing] by myself without depending on others,” Orville learned about a new mode of living and through his experience of making a map he learned that “even though I may not be able to make friends with too many people [. . .], the
creativity and the imagination and other things like that, even practical aspects of making a map, were there with me.”

Life lessons of 2 participants, Jimmy and Geoff, involved learning about others. For Jimmy, his experience of living with his last girlfriend was an important learning experience because it taught him about “looking at other people differently”: “that you always have to put yourself in someone else’s shoes and that no one really knows anyone else.” Likewise, Geoff also started to look at people, women in particular, differently after his spiritual awakening. He said, “I just think before that I was in some ways very self-centered, and I was very aware of my own suffering but not so much others’.” He explained:

I started to understand women in general a little better, and they weren’t as mystifying to me, and I started to realize, you know, that just because a woman was, you know, young and smart and beautiful, [it] didn’t mean that she didn’t have any problems.

As these examples illustrate, most autistic participants in this study did not seem to have any difficulties with autobiographical reasoning.

9.3.3.8 On Pierre’s (Not) Talking with Others about His Life Experiences

Pierre did not seem to talk much with others about his life experiences. Although he said that he “occasionally” shares his good experiences with others, he could not identify anybody with whom he did so. Most importantly, he did not talk to anybody about his negative experiences until he was in his late 20s, when he first revealed his most painful experiences to his university counselors, and later to his family and a psychiatrist. The fact that Pierre did not discuss his thoughts and feelings with his parents at the time he was hurt is interesting for several reasons; I focus on two of them: construction of self-narratives and coping.

Construction of self-narratives. Many scholars have suggested that child and caregiver conversations play a crucial role in the development of autobiographical memories and the construction of self-narratives and self-understanding. It has been suggested that through conversations about their experiences children learn what is appropriate to remember and how to remember it, as well as how to talk about their experiences and evaluate them (Fivush, 1994; P.
J. Miller, 1994; Nelson, 1988, 1993; Thorne, 2000). Furthermore, it is well known in psychology that people find that talking about personal experiences enhances their self-understanding (Pennebaker, 1997; Pennebaker & Graybeal, 2001). Given that difficulties with communication are a defining characteristic of autism (APA, 1994, 2000), autistic individuals seem to be at an enormous disadvantage in terms of opportunities for the development of autobiographical memories, autobiographical reasoning, and self-understanding. As is well known, autistic individuals have an intense disinterest in dialog and a preference for monologue (Attwood, 2006). As Donna Williams (1992) explains:

> When I was in a talkative mood, I would often talk on and on about something which interested me. The older I got, the more interested I became in things and the longer I would go on about them. I really was not interested in discussing anything; nor did I expect answers or opinions from the other person, and would often ignore them or talk over them if they interrupted. The only thing that was important to me was to talk in an effort to answer my own [italics in original] questions, which I often did. (p. 51)

Children with Asperger syndrome also prefer to talk about encyclopedic knowledge and factual information (Attwood, 2006; Szatmari, 2004; Vuletic et al., 2005) and rarely talk about their experiences (e.g., Gerland, 1997; McKean, 1994; Newport, 2001; Prince-Hughes, 2004; Robison, 2008; Sainsbury, 2000; Shore, 2003; Williams, 1992). As Dawn Prince-Hughes (2004) explains, “I never told my parents about [an incident with a third-grade math teacher]. It didn’t occur to me that I could communicate about things that happened. I simply wasn’t able to understand that use of words” (p. 43). Likewise, Stephen Shore (2003), who “lived in terrible fear of getting ‘beat up’ at the end of every school day” (p. 53), wrote that the idea of talking about his bullying experiences to his parents “never occurred to [him]” (p. 56).

Given this lack of engagement in the social construction of the meaning of their experiences, from the perspective of social construction of self-narratives then, Pierre’s self-narrative (as well as those of other autistic individuals) should be profoundly different, if not impossible. However, Pierre’s self-narrative does not contain any obvious indicators of such profound difference (nor do self-narratives of many other autistic individuals), except, perhaps, for the relative lack of use of emotion words. However, such absence is not uniquely related to autism; indeed, it may stem from several other sources, such as individual differences in providing self-reports (Barrett, 2004), personality style (Magai & Haviland-Jones, 2002), gender (Barrett, Lane, Sechrest, &
Schwartz, 2000; Mulac, Bradac, & Gibbons, 2001), culture (Lutz, 1982), or a neurological disorder called alexithymia (J. G. Taylor, 1984). And although many autistic individuals do show difficulties with identifying and describing emotions (Asperger, 1944/1991; Attwood, 2006; Begeer, Koot, Rieffe, Meerum Terwogt, & Stegge, 2008; Hill, Berthoz, & Frith, 2004), and Attwood claimed that the “inner world of emotions appears to be uncharted territory for people with Asperger’s syndrome” (p. 130), this is not always the case. For example, Dawn Prince-Hughes (2004) used not only many emotion words when describing her emotional experiences, but she also vividly described them, as the previously-quoted excerpt from her autobiography—in which she described how her mind swam when her teacher yelled at her—illustrated.

Coping. Talking to parents or caregivers is also suggested to be one of the important ways in which typical children cope, as well as learn how to cope, with stress (Fivush, Berlin, Sales, Mennuti-Washburn, & Cassidy, 2003; E. A. Skinner & Zimmer-Gembeck, 2007). Parents also play a crucial role in children’s interpretations, clarifications, modifications, and reframing of their memories (Pillemer, 2001)—negative and traumatic ones in particular. Further, according to Pillemer, “If the memory can be reinterpreted in terms that are motivating rather than demoralizing, it will be transformed from a limiting force into an enabling one” (p. 131). Indeed, research has shown that supportive social environment can facilitate such “posttraumatic growth” (Tedeschi & Calhoun, 2004; see also McAdams, Reynolds, Lewis, Patten, & Bowman, 2001).

From this perspective, not talking about negative experiences means not having the opportunity to reframe or “repair” (Howard, 1991) one’s initial interpretations of unpleasant events. For example, Pierre’s interpretation of his teacher’s criticism was (and still is) that it was an act of deliberate humiliation. However, although, as reviewed in the section on bullying, this may be a valid interpretation, there are other, proactive, and more beneficial interpretations of the same behavior that Pierre may not have considered because he did not have the opportunity to hear others’ perspectives. For example, as Pillemer suggested, even sharp and insensitive criticism could be a teacher’s expression of interest and confidence in a student’s potential for improvement. In other words, it is possible that Pierre’s “insensitive” teachers simply wanted to encourage him to put more effort into his work because they recognized his potential.
From this perspective then, the fact that Pierre has recently started talking to his therapist and his parents about his childhood pains would suggest that he may well be on the way to “repairing” his negative experiences. However, so far, he said, talking only gave him “some satisfaction” because it allowed him to express his position (“where I stood”), which he felt could be progress (“maybe”). Although trauma literature clearly suggests that expressing one’s feelings is necessary for recovery from trauma, it also suggests that it may not be sufficient (Pennebaker, 1997). Indeed, the extensive body of literature seems to agree that true recovery, and “posttraumatic growth,” requires new insights and new interpretations of memories of upsetting experiences (Nemeroff et al., 2006; Pennebaker, 1997). And although a more common way of arriving at new interpretations is through hearing about them from others, self-discoveries are also possible, an example of which will be discussed in the next section.

9.3.3.8.1 Other Participants

Like Pierre, apart from mental health professionals, the other participants in this study also did not remember talking much—if at all—with others about their experiences, and even that much later after the occurrences of the significant events. Four participants (Mike, Geoff, Howard, and Jimmy) said that at the time of the experiences they did not talk to others, whereas 3 participants (Sarah, Orville, and Alan) mentioned people with whom they did, or might have, talked about at least about some of the significant events from their lives; however, they did not remember any details from these conversations and often used vague terms such as maybe, probably, and usually in their replies to the question asking for details. Two participants, Sarah and Alan, mentioned talking to their parents and their aunts, and 1, Orville, to his friends.

Four participants, Mike, Geoff, Sarah, and Orville, mentioned specific difficulties associated with talking about their experiences. However, the nature of these difficulties was different for each participant. For Mike, the difficulty seemed to be in his inability to express himself, at least when he was a child. Thus, talking about one of his childhood experiences involving physical bullying, he said,

And I couldn’t . . . you [lifts his hand from the table and drops it back making a sound] know . . . what happened . . . but even though [the same movement and sound] my
parents asked me [the same movement; a bit louder sound] what happened, [the same movement; louder sound] I couldn’t explain [starts tapping] it to them completely [stops tapping], and . . . [the same movement and sound] stuff like that . . . [the same movement; louder sound] and made me feel bad.

On the other hand, for Geoff, who said that “it’s hard” to talk to others about his experiences, even in adulthood, the main issue seemed to be trust, as he himself suggested: “I think I had some pretty serious trust issues.” However, he said that he was getting more comfortable with talking as he was getting older: “When I was younger I had trouble even opening up to therapists, other people, no way. Now, I’m much better. I’m very open with therapists, and I’m becoming more open with other people.” One of those other people was a friend to whom he recently talked about one of his significant life experiences:

Eventually, maybe couple of years after it happened, I made a friend who later became my girlfriend—long-distance relationship—and we had a lot in common in terms of our interest in spirituality, so I was able to talk to her about it quite easily.

Sarah also admitted that she does not feel comfortable talking to others about her experiences, negative ones in particular. She said, “I usually don’t want to talk [to parents] about the bad stuff that happens at work.” However, her reason for not talking is her belief that she alone has to deal with her problems.

For Orville, who tried talking to others—at least in his adulthood—but did not find it useful, the main issue seemed to be that of others’ not understanding his perspective, which made him believe that there is no point in sharing his experiences. He said that when he tried to talk about one of his negative experiences, none of the people understood him:

To other people it’s not important at all in any way, so they just don’t want to hear about [it], so how can I do discuss it anymore? And they change the subject, and that’s it, so. And again, when they say to me, “I don’t understand why you are dwelling on this subject for?” I try to tell them, “I am not dwelling on it, it’s just a moment of my life I feel is important, that’s all.

In contrast to Orville, Geoff said that talking to a friend was “overall” a positive experience; however, he added that “it doesn’t really feel like something that I feel compelled to talk about necessarily. I think my primary means of talking about it is by putting in a book, for sure.”
Indeed, as already mentioned, Geoff made many references to his writing about his experiences as a main, albeit recent, means of understanding them. For example, when talking about one of his most important life experiences, of getting the first radio, he said, “This is actually something that I didn’t really share with anybody because I wasn’t really conscious of it myself until I wrote about it and realized, My god, this is so huge in my life.”

Finally, it is also interesting to note that 2 participants, Geoff and Mike, found that talking about their experiences during this study’s interview sessions was a potentially useful experience for their self-understanding. For example, Geoff said, “It was interesting for me to try to look at myself and maybe explain a few things about myself in a way that I wouldn’t ordinarily do it. So that was kinda an interesting exercise.” Likewise, Mike said,

> It’s different. It’s probably . . . it gives me [lifts his hand from the table and drops it back making a sound] a better understanding, maybe, of who I am, where I was, and where I’m going; that’s what I think about it.

### 9.3.3.8.2 Interpretive Summary

Like other autistic individuals who wrote autobiographies, most of the participants in this study did not have a habit and/or need to talk about their experiences with others, either in childhood or in adulthood. However, at least 1 participant (Geoff) seemed to feel more comfortable with talking about his experiences as he got older, whereas 3 others seemed to have the desire but were lacking in opportunities to talk to people who were willing to listen to them with an open mind.

Several participants expressed some difficulties with talking to others, and 1 participant (Geoff) described how instead of talking he found writing about his experiences to be more beneficial for meaning making of his experiences as well as for his self-understanding. Geoff’s words seem to echo the sentiment of many other autistic individuals who find it more natural and/or easier to “talk” about their experiences by writing about them (e.g., Gerland, 1997; Grandin & Scariano, 1986; Lawson, 2000; Sainsbury, 2000; Shore, 2003; Williams, 1992). Most importantly, he suggested that through the process of writing he was able to reframe and repair his painful life
experiences, which may have a direct bearing on the above discussion of possible roads to reframing of traumatic experiences.

9.3.3.9 On Self-Perceived Significant Influences on Pierre’s Life

Pierre felt that his family had the most influence on his life. Importantly, despite occasionally implying blame on his parents for some of his unpleasant childhood memories, he said that he never “dreamed” about having different parents. And although he said that he was always learning from his family, he could not provide specific examples for things he learned from them (thus, once again exhibiting his difficulty with retrieving specific memories).

Although there are no studies that explore autistic individuals’ perceptions of important influences on their lives, much like Pierre, many autistic autobiographers explicitly acknowledge their parents’ positive influences (e.g., Barron & Barron, 1992; Grandin & Scariano, 1986; Purkis, 2006; Shore, 2001; Tammet, 2006). However, others have also expressed their parents’ negative influences and pointed to their lack of understanding, neglect, and even abuse (e.g., Gerland, 1997; Lawson, 2000; McKean, 1994; Mór, 2007; Prince-Hughes, 2004; Robison, 2008; D. Williams, 1992).

Pierre did not exclude the possibility that some of his teachers and other people he met in school could also have influenced his life; however, he could not remember any particular person that had such an influence. Although like Pierre, other autistic individuals most often mention their experiences with their teachers negatively (e.g., Prince-Hughes, 2004; Sainsbury, 2000), several wrote that they had caring and supportive teachers or mentors and were grateful for their help, trust, and encouragements. Moreover, they feel that without them they would not be where they are now nor as satisfied with their lives as they are (e.g., Grandin & Scariano, 1986; Grant Lissner, 2000; Prince-Hughes, 2004; Shore, 2001; D. Williams, 1992).

9.3.3.9.1 Other Participants
**Mike.** Like Pierre, Mike also attributed the greatest influence on his life to his parents. He emphasized their efforts to help him as much as they could—getting the right education in particular. Talking about his mother, he said, “She just always tried to help me, basically. She taught me how to read.” However, Mike had much more to say about his father, who he looked at as a role model, and without whom, he felt that “[he] probably wouldn’t have been as successful as [he was].” He described his father as follows:

He’s also a role model, hard worker. He does more than he says. He thinks through his actions. He’s also a great provider. [He] worked very, very hard, and I obviously looked at him as an example; he provided a great example of taking care of your kids, taking care of our family, being a good role model in the community, and I’ve learned a lot from him, like that.

In addition to his parents, Mike also recognized the important role of “[his] wife, probably—to a degree” because she “encouraged [him] to be successful.”

**Howard.** Howard’s parents were also the most important in his life. Describing their importance, he said, “They guide me, they show me what to do, they taught me well, those types of things.” Howard also attributed significant roles in his life to some of his teachers, group leaders, doctors, and grandparents. Talking about the importance of some of the group leaders, he said, “They’re good. [. . .] They helped me . . . they taught us life skills; we picked topics and they presented new topics every week.” He particularly remembered “employment skills, like, employment rules, authority and respect; Aspergers’ [and] autism problems, like, how we live with our problems.”

**Sarah.** Sarah also credited the most significant influence on her life to her parents. She said that without them her life would “probably [. . .] have been more difficult. I would not be really happy . . . [I would] be, like, depressed and stuff.” She assigned a similar significance to the role to her honorary aunt.

**Jimmy.** To Jimmy, whose parents divorced when he was an adolescent, the most important people were his mother and his sister. Talking about his mother’s role in his life, he said, “Just because of her consistency, she’s always been there.”
Orville. Orville also credited his parents with being most influential on his life because “they treated [him] the same as everybody else,” that is, the same as his four siblings. In addition, he also felt that a social worker, whom he started seeing in his adolescence, and whom he considered a friend, had an important role in his life because he “saw potential” in him, talked to his parents about ways to help him, and was a “connecting link with other people.”

Alan. Unlike other participants, Alan credited his psychiatrist and aunt with having the most influence on his life. When asked about the role of his parents, he said that they “used to be important and they’re not so much these days because I feel more [involved with] my own things.”

Geoff. Geoff was the only other participant who did not mention the role of his parents. Instead, he attributed his (dead) cousin with having the most significant role in his life, as previously described. He also acknowledged the roles of several other people or groups of people: “the first girl I fell in love with, the one who got me out of the emotional shut down;” the “people that I don’t know, but are musicians, you know, role models, or musicians that I really identify with in some way,” and “Grade 10 English teacher” because

I think in some ways he might have kick started my creativity and given me an appreciation for, I don’t know, sort of a sense of the absurd that I may not have had up to that time because I was very serious and literal.

9.3.3.9.2 Interpretative Summary

Like Pierre, other participants also credited their parents with having the most significant influence on their lives. In fact, only 2 participants, Alan and Geoff, considered some other people as being more influential. These other people included a psychiatrist, an aunt, a teacher, former romantic partners, and personally unknown celebrities (as role models). Overall, the participants mentioned positive roles of romantic partners26 (3 participants), specific teachers,

26 One of these persons assumed her special significance after her death—in the role of a spiritual guide.
doctors, and relatives (2 participants each); as well as the roles of siblings, social workers, group leaders, and grandparents (1 participant each).

The important influences identified by this study’s participants are consistent with the autobiographical literature, which often contains reports emphasizing the crucial roles of autistic individuals’ parents (e.g., Barron & Barron, 1992; Grandin & Scariano, 1986; Purkis, 2006; Shore, 2001; Tammet, 2006), and, less frequently, teachers (e.g., Grandin & Scariano, 1986; Grant Lissner, 2000; Prince-Hughes, 2004; Shore, 2001; D. Williams, 1992), romantic partners (Lawson, 2000; Prince-Hughes, 2004; Tammet, 2006), siblings (Kolinski, 1995; D. Williams, 1992), and doctors (D. Williams, 1992; Dumortier, 2004).

It is also interesting to note that 2 participants mentioned having role models—Mike, his father; and Geoff, personally unknown musicians—as references to role models are relatively uncommon in autism literature, including autobiographies. Role models mentioned by other autistic individuals include teachers (e.g., Hadcroft, 2004; Purkis, 2006) and siblings (Kolinski, 1995).

### 9.3.4 Pierre’s Future Orientation

Pierre’s (personal) future thinking revolves around two wishes: to get a job and a girlfriend. However, Pierre admitted that he does not spend much time thinking—or talking with others—about either, which was also evident from his vague answers. For example, he said that he would like to have a “good job,” by which he meant a job that he “really enjoyed,” such as working in the library (he enjoys “being around the books all the time”), and/or which also “uses [his] talents,” such as translating and becoming a writer and “writing good books.” As already discussed, he was even vaguer with regard to the next steps towards obtaining such a job, which included “find[ing] a new job training organization” and updating his CV—both of which he had on his to-do list for more than a year.

Likewise, although Pierre said that he would like to have a girlfriend and “a wife someday” (he was “not so sure about family”), he did not have much more to say about this wish. He also
mentioned that he would like to have “a home of his own,” “get new friends” and have “political influence” so that he could make “the world a better place.” However, as already discussed, at the time of the interview (as well as after a follow-up almost a year later), Pierre was only actively pursuing getting new friends through Meetup gatherings.

Pierre’ relative vagueness about his future contrasts his elaborate thinking about the future of the world, which he often writes about on the Internet and discusses with his friends. It is also in contrast with his claim about his imaginativeness. Although Pierre’s not having a clearer vision of his future is in line with the literature suggesting that autistic individuals might have some difficulties with imagination and/or planning (J. Craig & Baron-Cohen, 1999; Hill, 2004; Jordan, 1997; Ozonoff, 1995; Wing, 1981), this interpretation is clearly limited to his personal future. However, the contrast between personal and world future orientation is more consistent with a difference in knowledge about the domains in question: employment and dating, on the one side, and history and politics on the other side—the latter being both his expertise and hobby. As already discussed, Pierre’s elusiveness is also consistent with his lack of “decisiveness,” as he termed his difficulties, as well as with a tendency to procrastinate.

It is interesting that although Pierre said that he would not like it if the book about him ended with “Nothing much else happened to him […] and he continued to live with his parents;” he did not seem to be actively seeking ways of preventing this from happening. Given that he also believed that his future depends 80% on him, his lack of proactive thinking seems puzzling. Even if his main difficulty stemmed from a lack of knowledge about the domains in question, given his intellectual abilities and love of learning, it is still puzzling that he did not make any serious attempts at mastering them. One obvious possible answer is that Pierre may be more satisfied with his life than his wishes suggest. Alternatively, it is possible that because of his high intellectual abilities, which allowed him to be academically successful, he did not have enough opportunities to develop adaptive coping strategies for dealing with failures, such as problem solving, cognitive reappraisal, and goal restructuring (for a recent review of coping strategies, see Skinner & Zimmer-Gembeck, 2007). Instead, he may have adopted avoiding as his main approach to dealing with failure, which is consistent with already discussed consequences of being bullied, as well as with his self-evaluation of getting discouraged easily. Finally, it is possible that Pierre’s chronic traumatic bullying experiences have lead to the development of a
present-oriented thinking style (Terr, 2003) or even to “temporal disintegration,” where present, past and future are isolated from each other, a phenomenon common among trauma victims (Holman & Silver, 1998).

It is also interesting that despite not being proactive with regard to his main wishes, Pierre was optimistic that he will obtain his desired and avoid undesired future (60% and 70% confident, respectively). This optimism is in contrast to research and clinical evidence suggesting that autistic individuals might be prone to a pessimistic cognitive style (Barnhill & Myles, 2001; Gillberg, 2002; respectively), but is in accord with autobiographical evidence suggesting that at least some autistic individuals could also be very optimistic (e.g., Barron & Barron, 1992; Grandin & Scariano, 1986; Holliday Willey, 1999; Mitchell, C. 2005; Slater-Walker & Slater-Walker, 2002). For example, like Pierre, Christopher Slater-Walker (Slater-Walker & Slater-Walker, 2002) remained optimistic that he will find a romantic partner without having any clear thoughts about it. As he put it,

I never had any clear idea about exactly how I would meet someone appropriate, and I was very conscious of the perceived fact that “people like me” tend to keep themselves apart from the general interaction which enables meetings to take place. This of course could lead to frustration, and it wasn’t always easy to remain optimistic about it, but in general I always thought “something would happen” without having any clear idea of what it would be. (p. 18)

9.3.4.1 Better World

Pierre said that the world would be a better place for him if he knew which of his skills were “in real need”; that is, if he knew how “to put [his skills] to [the world’s] use” (“I know I have some skills, I’m just not sure about what use the world would put them to”). Pierre’s wish to contribute to the world is consistent with similar wishes expressed by other autistic individuals (e.g., Grandin; in Sacks, 1995; McKeown, 1994; Tammet, 2006). For example, Thomas McKeown (1994) wrote, “I want to contribute and I am unable to. And this makes me profoundly sad” (p. xv).

Likewise, in her well-known interview with Sacks, Temple Grandin (Sacks, 1995) remarked, “I want to make a positive contribution—know that my life has meaning. Right now, I am talking about things that are at the very core of my existence” (p. 296).
Although Pierre did not have any specific suggestions about making the world a better place for autistic people, he said that he had many ideas about making the world a “better place for everyone,” including “chang[ing] the world in way that promotes justice.” As already discussed, Pierre’s future-oriented thinking concerning the welfare of human kind is in sharp contrast with his lack of future orientation in regard to his own future. However, it is in line with both expert (Attwood, 1999, 2006; Baron-Cohen, 2005) and self-reports (e.g., Barron & Barron, 1992; Holliday Willey, 2001; McMullen, 2000). For example, Attwood (1998) wrote that autistic individuals have “a strong moral code and sense of justice” (p.179), which Penelope McMullen, (2000) documented as follows:

I participated with organizations that worked to end the Vietnam war, the arms race, and racism and sexism, and to promote better conditions for farm workers. I am currently working on nuclear pollution issues. Nonautistic people also work for social justice, but I believe it is important to note the work of those with autism, because people with autism are often mistakenly thought to be too self-centered to care about other people’s problems.

9.3.4.1.1 Other Participants

There were both similarities and differences between Pierre’s and other participants’ future-oriented thinking. In this section, I review the most salient features of the participants’ accounts, relating to the degree, content, elaborateness, and abstractness of, as well as to the levels of optimism, personal agency, and difficulties with future-oriented thinking.

**Degree of thinking and talking about future.** The level at which the participants engaged in future-oriented thinking ranged from relatively low (3 participants; Orville, Jimmy, and Howard) to relatively high (4 participants: Sarah, Alan, Mike, and Geoff). For example, when asked whether he thinks about himself in the future Orville said,

A little bit. I’m in my 60’s now, heading towards old-age pension in a couple years, no really so much to plan as far as education or other things, but still . . . [I] don’t know what else to do other than enjoy life more or less day by day as it comes.

Orville also said that he does “not really” talk much about his future with others. Likewise, when Jimmy was asked whether he thinks about his future, he replied. “Not too much. I do . . . yeah.”
However, when asked about his goals over the next 5 years, he replied, “None.” Like Orville, he also said that he did not talk about his future with other people, not even with his psychiatrist.

Similarly, although when asked whether he thinks about his future, Howard replied, “I do. I think about winning the million dollars, winning the lotteries, retiring at forty,” when his whole account of his future is considered—including the statement “I don’t have any goals” and his negative response to the question of if he talks to others about his future—it becomes obvious that his initial response was not more than what it seems to be at first glance, an attempt to be humorous rather than an indicator of a true future orientation.

In contrast, Alan said that he thought about his future “quite a number of times,” and that he also talked about it with his psychologist, his brother and his wife, his aunt, and his parents, about whom he said, “I’ve talked with them many times.” Accordingly, throughout the interview, he made numerous references to his future, more than any other participant.

Given the difference in age and life situations of the participants, the difference in the degree in which they engage in future-oriented thinking is, to some extent, understandable. For example, Orville’s relative self-reported lack of future orientation could be, at least in part, explained by his relatively advanced age and retirement status. As research has shown, self-reported future-oriented thinking, and planning in particular, decreases with age (Prenda & Lachman, 2001). Some of the differences could also be attributed to well-known individual differences in future-oriented thinking (Zimbardo & Boyd, 1999) as well as to differences in executive functions (Fuster, 2003; Stuss, 1992). However, although autism is linked with executive dysfunction (Ozonoff, 1995), it is also associated with depression and anxiety (Castaneda, Tuulio-Henriksson, Marttunen, Suvisaari, & Lönnqvist, 2008)—two other conditions that this study’s participants have also been diagnosed with.

**Thematic content: Desired future.** Future-oriented thinking of other participants involved the same domains mentioned by Pierre, as well as some new ones. (For a full list of domains, see Table 11.) Thus, finding a partner was mentioned by all except one other participant (Howard). For example, Sarah and Alan included “maybe getting married and maybe having a family” and “find[ing] girlfriend [and] maybe having family,” respectively, on their lists of best possible
Table 11 Summary of Participants’ Desired Futures

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Component</th>
<th>Example</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Desirable future</td>
<td>Normative</td>
<td>Partner</td>
<td>Full-time (P, S, A, G, J); new career (M, H)</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Employment</td>
<td>All participants who were unemployed</td>
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<td></td>
<td></td>
<td>Independent</td>
<td>All participants living with parents</td>
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<tr>
<td></td>
<td>Non-normative</td>
<td>Leisure</td>
<td>Traveling (M, O, A, G, H); life enjoyment (M, O, S); learning (M, S); moving (A, G)</td>
<td>7</td>
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<tr>
<td></td>
<td></td>
<td>Social</td>
<td>Helping others (M); bringing up children (M); “meet[ing] lots of friends” (M)</td>
<td>1</td>
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<tr>
<td></td>
<td></td>
<td>activities</td>
<td>“Fix[ing] the house” (O)</td>
<td>1</td>
</tr>
<tr>
<td>Better world</td>
<td>Self-focused</td>
<td></td>
<td>“A life without autism—with a million dollars.” (H)</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>All people</td>
<td>E.g., world without violence (S), market economy (O), and dress code (G); world where everybody would be fair to everybody (M); were people would be “more friendly [and] non-judgmental” (J); where people would know how “to put [their skills] to [the world’s] use” (P)</td>
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<td>including</td>
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<td></td>
<td>Self-and-other-focused</td>
<td>themselves</td>
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<td>All autistic</td>
<td>E.g., world where autistic individuals would be accepted as they are (M, O, J)</td>
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<td>themselves</td>
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<tr>
<td>Other-focused</td>
<td></td>
<td></td>
<td>World where everyone’s basic needs (e.g., food and shelter) would be met (S) and a world where an important aspect of schooling would include learning social skills (G)</td>
<td>2</td>
</tr>
</tbody>
</table>

Note. A = Alan; G = Geoff; H = Howard; J = Jimmy; M = Mike; O = Orville; P = Pierre; S = Sarah.

aAll participants who were unemployed.
bAll participants living with parents.

futures. Likewise, Jimmy and Orville’s wish lists contained “meeting the woman of my dreams” and “[having] a relationship of bonding with somebody with a lot of similar connotations and
empathy.” Geoff had more to say: “meet[ing] somebody, whom I love very much and it’s really the first relationship I’ve ever had where everything is clicking,” and

I envision this person in some way being an artist. She doesn’t have to be a writer or a musician, but I envision that the person who would really understand me would be an artist. So I think a lot of what we do would be, you know, art related, culture related.

Given the nature of autism—that is, that the focus of autistic individuals is, by definition, on themselves and that they find social relationships either undesirable or difficult—the fact that all but one participant included relationships in the repertoire of their desired futures should not be taken for granted. Whereas it could be argued that at least some of the participants in this study perhaps included the relationships as part of their desired future because they knew that it was something expected of them based on the lack of conviction in some of the accounts (e.g., those prefaced by “maybe” and/or lacking details, which will be discussed next), the same could not be argued for all participants. In fact, half of the participants (Orville, Mike, Geoff, and Jimmy) clearly demonstrated that their inclusion of relationships in their possible selves stemmed not from what was deemed socially desirable, but for their deeply felt needs. In addition to being an important theme of their entire accounts (as previously reviewed), the above-cited phrases—which include “the woman of my dreams,” “somebody with a lot of similar connections and empathy,” and “somebody, whom I love very much”—also testify to this: it was not just having a relationship that they desired, but a relationship with a particular kind of person who could potentially meet their needs for relationship and intimacy. Moreover, Orville and Geoff also demonstrated that they really did not try to emulate any of the socially desirable behaviors unless doing so was logical to them. (Although, as already discussed, the same was true for Pierre in all other aspects of his life, this could not be said with the same conviction in regard to the domain of social relationships.)

This study participants’ inclusion of the relationship theme in their desired futures is in line with autobiographical accounts of autistic individuals, where future relationships are often one of the most prominent themes (e.g., Dumortier, 2004; Edmonds & Beardon, 2008; McKean, 1994; Miedzianik, 1986). However, it should be noted that, like Howard, the desired future of Temple Grandin (1995c), who chose celibacy, never included a relationship theme, nor did those of John Smith Boswell (2008), who declared that people are not his “first priority,” or Edgar Schneider
(1999), who claimed not to have “an emotional void that needed to be filled by another person” (p. 57).

Two other domains mentioned by Pierre, *work* and *independence*, were also present in accounts of all the other participants who did not have either full-time employment (4 participants) or who still lived with their parents (3 participants). However, participants formulated work-related goals very differently: for Alan, it was “find[ing] a good job that will pay well”, for Sarah, “getting a full-time job”, for Jimmy “getting a job that I like [and] being successful at it”, and for Geoff,

working in some kind of creative career that I find stimulating and interesting—whether that be with words or music, whether it be that I’m an author. I could be an editor. I could be something else. It could work out, but I should be working in the arts. That’s sort of the bare minimum.

Moreover, work-related items were also mentioned by 2 other participants who already had full-time jobs at the time of the interview, Mike and Howard. Thus, Mike included “start[ing] a new career” (after the imminent retirement) among his goals for the next 5 years, whereas Howard included “get[ting] an accountant’s position” among his best possible futures.

As previously reviewed, themes of work and independence are often found in the autobiographical accounts of unemployed and/or dependent autistic individuals (e.g., Grant Lissner, 2000; Romoser, 2000; for an exception, see Miedzianik, 1986).

Among the several new domains of future-orientated thinking mentioned by the participants, three were present in more than one of the participants’ accounts: *traveling* (mentioned by 5 participants: Mike, Orville, Alan, Geoff, Howard), *moving* (to another city or country; mentioned by 2 participants: Alan and Geoff, respectively), and *learning* (“going back to school” and learning to drive; also mentioned by 2 participants: Mike and Sarah, respectively). Here is Geoff’s account of his need to move away from his hometown:

I don’t know if this is true for everybody, but it really feels true for me that there is some sort of growth that I want to experience by moving away from the place I grew up. And, you know, like, [Montréal] is a great city and all that—it’s a really nice hometown to be
able to say, This is my hometown—but I’m kind of sick of it, and I wanna live somewhere else.

Other domains mentioned by only 1 of the participants included: helping other people, bringing up and taking care of children, and “meet[ing] lots of friends” (Mike); and household duties (“fix[ing] the house”; Orville). In addition, 3 participants also mentioned general wishes to enjoy life (“to enjoy life more”; Orville) and be happy (“just being happy”; Sarah, and “just trying to be happy”; Mike).

Taken together, this study’s participants’ desired futures were in accord with those of non-autistic adults (Bybee & Wells, 2002; Cross & Markus, 1991; Hooker, 1999). That is, they included both developmentally-relevant tasks (i.e., socially constructed normative tasks) related to occupation, relationships/family, and independence, and personally-relevant themes such as learning, leisure activities, and household duties. Moreover, the participants’ accounts also reflected age-related changes in the repertoires of the desired futures (Brandtstädter & Rothermund, 2002).

**Thematic content: Wishes.** In addition to the themes participants mentioned as being part of their desired futures, they also had a number of wishes, both self- and other-related. Four participants (Alan, Geoff, Orville, and Mike) had the same wish: to be accepted for who they are. For example, Alan wished others would “understand me and try to accept me for what I am,” and Geoff said, “I hope that I will experience, maybe for the first time, putting my true self out there and being accepted instead of being rejected.” Similarly, Orville wished for “a far better acceptance and respect”:

I mean having it so that when I do communicate with people, they have a far better acceptance and respect in the broadest sense of those two terms—not that they have to agree with me, but they let me have the say, they don’t just stop me and say, “Stop right there! We don’t want to hear anymore” type of thing. They let me carry on; then if I stepped down, and somebody else wants to stand up, like in a debate, and refute what I said, I don’t mind that, but it’s when I [am] not permitted to have any say at all in the matter as though, whether it’s the person I am talking to alone or the group I am involved with as a whole, if I raise a possibility—even if it is just in brainstorming—like, on ending poverty issues, “What about the possibility of such and such?” and they look at me, “You know that’s impossible,” and they change the subject immediately. Well, that’s why I find there’s just lack of acceptance or respect.
Wishes of 5 participants (Sarah, Alan, Mike, Geoff, and Orville) concerned others. For example, Mike wished for “[his] kids to grow up and do the best they can do,” whereas Sarah was more cosmopolitan and wished for “world peace, no violence in the world; everyone to have their own home in the world [. . .], everyone to have food too.” In addition to being concerned with others, Alan, Mike, and Geoff also saw their own roles in improving the lives of other people. Thus, Alan said that he would like to “try to make life better for others, make someone happy, make life better for, not just for you or for person who you want to be with, but for other people around you.” Likewise, Geoff, talking from his own experience, wished people would understand themselves better, and he wanted to inspire them to do that:

> I personally think the world would be a much better place if each person [long pause] embarked upon a quest to discover why they were here, what they were doing here, what their true purpose was. So my wish for the world, for people in the world, is that—and maybe that’s partly what I’m trying to inspire in writing this book—is that each person, sort of, goes on their own vision quest whatever it may be, to find out who they really are, what they really want. I think the world would be a wonderful place if every single person did that. That’s just my opinion, but that’s a wish I would have for the world.

Orville wished for better understanding of all autistic individuals, to which he tries to contribute by sharing his experience of living with autism:

> Total better—not just global—but common understanding of what person means when they mentioned Aspergers or autism and that, because when people mention other conditions out there, or lifestyles, or whatever you wanna call them . . . people don’t say What’s Alzheimer’s, I never heard of it before? or anything. So it’s that public understanding that when I say that [I have] this condition, the public doesn’t fear as though it’s a terrible thing, or something, but understands it a lot better and what goes with it.

This study’s participants’ wishes are surprising in that they clearly show their concern for others’ welfare, which is rarely, if ever, attributed to autistic individuals. Indeed, a lack of concern for others is considered one of the defining features of autism (Asperger, 1944/1991; Gillberg et al., 2001).

**Thematic content: Undesired future.** As would be expected, some of the undesirable futures were direct opposites of the desired ones; they included both developmental tasks (i.e., work,
independence, and relationships) and personal goals (e.g., moving away). Thus, 4 participants (Sarah, Orville, Mike, and Geoff) selected *not having (particular kinds of) relationships*, 3 participants (Sarah, Orville, and Alan) had visions of themselves *not living independently*, and a further 3 participants (Orville, Mike, and Geoff), *not having a (desired or current) job or financial means*. However, although the themes of their undesired futures were similar, the components of the visions behind them were rather different. For example, Sarah expressed her relationship-related undesired future as “not getting married,” Mike, as “my marriage wouldn’t work out and I get a divorce,” Geoff, as “I wouldn’t want to stay stuck where I’ve been all my life in terms of relationships, and unable to move forward, or unable to connect,” and Orville, as

> Just more and more people, as I become senior, just don’t wanna associate with me. [...] I end up in some seniors’ home, and nobody else in that seniors’ home can understand me, and [taps] there I am, practically left in my room living in isolation until the day I die—I wouldn’t want it to end that way.

Participants also had very different visions of not living independently. As quoted above, for Orville it meant losing his house and “end[ing] up in some senior home,” for Sarah, it meant, “If for whatever I can’t handle living on my own, then I have to move back home;” and for Alan “being arrested, or being [in an] asylum.” He provided the following description:

> I could be going to some crazy place where people are even more nuts than I am, or somebody . . . like a crazy asylum, like in the movie *12 Monkeys*. [...] I could be beat . . . murder somebody, you know, when I get so upset and beat them to death, and I could be arrested and charged.

Although unrelated to independent living, one of Geoff’s undesired futures was related to the place of living. For him, “If I had to live in [Montréal] forever . . . actually the worst would be having to live back in the neighborhood I grew up in—that would be the worst.”

Working and a related financial-means theme involved not “mak[ing] any financial [gains/means]” (Orville), “none of my books [being] published” and “working at some dumb job” (Geoff), and losing a job (Mike):

> Well, I guess, worst possible outcome is that, you know what I mean, you screw up at work [taps], you lose your job, stuff like—that would be the worst possible outcome. [taps] And that . . . for me, that they say, “You have a mental disorder; you’re leaving; we are getting [shortened] rid of you, you’re . . .” You know what I mean?
Other visions of undesired futures shared by more than one participant were related to health and death, both of self and others. For example, 3 participants (Howard, Jimmy, and Mike) mentioned undesired self health-related outcomes: “Get[ting] cancer” (Howard), “Getting a disease” (Jimmy), and getting diagnosed with a “mental disorder” (Mike) and 1 participant (Jimmy) also mentioned in relation to others: “Anything bad happening to anyone I know. My family or anything. [. . .] Getting a disease or something.” Death was mentioned by 2 participants: Howard did not want to “die young” and Sarah did not want her parents to die: “My parents dying, I would find that kind of sad.” Finally, Jimmy said that he would not like “dying and no one really knowing me. No one ever really understanding what the real me was when I thought about what I was really like.”

In summary, the participants’ undesired futures were consistent with their different life circumstances. Thus, although both Mike and Geoff had concerns regarding their jobs, in contrast to Mike, who had a job with which he was sufficiently satisfied, and who feared losing it, Geoff, who did not have a job, was afraid of not getting a desirable job and of being stuck with “dumb” jobs for the rest of his life. Likewise, whereas Mike feared losing his marriage, Sarah feared not having one.

This study’s participants’ undesired futures were similar to those of non-autistic adults (Bybee & Wells, 2002; Cross & Markus, 1991; Hooker, 1999). Additionally, in accord with Oyserman and Markus’s (1990) notion of “balance” in possible selves (that is, a balance between hoped-for and feared possible selves), this study’s participants’ undesired futures were, for the most part, well balanced with their visions of their desired futures. Although the health- and death-related themes did not have matching pairs among components of participants’ desired futures, which is also the case with non-autistic individuals (Bybee & Wells, 2002), they were clearly related to the themes of being happy and enjoying life. Indeed, by midlife, health is a crucial component of non-autistic adults’ feared selves (Hooker, 1999).

Elaborateness. As is already obvious from the above review, the participants differed with respect to the amount of detail they provided about their visions of their futures. Thus, whereas 3 participants (Sarah, Howard, and Jimmy) were, like Pierre, rather concise about their futures and
provided mostly lists of possible future experiences—with further probes usually not leading to additional details—3 other participants (Mike, Orville, and Geoff) provided very elaborate visions of their futures, which not only included many details but also alternative possibilities. Although the account of 1 participant (Alan) contained some specific details, overall, his account was neither as vivid nor as elaborate as the accounts from the latter group of the participants. The following excerpts illustrate the range of the levels of elaborateness. For example, when asked about his best possible future, Howard replied,

H: To win a million dollars and buy a mansion.
L: Okay. Anything else?
H: [pause] No.
L: What would you do with a million dollars, just buy a mansion?
H: Yeah, buy a mansion.

The next best possible future for Howard was “to get an accountant’s position,” but further probes did not lead to any new details. Jimmy’s reply to the same question—about his best possible future—was similarly brief: “Getting a job that I like, being successful at it, meeting the woman of my dreams.” In contrast, Mike’s response to the same question was as follows:

The best possible ending would be that we [prolonged; he and his wife], come together again as a couple, maybe in a different kind of . . . you know . . . things can never be exactly the same; that we go together in life; that our kids get older; that we, you know, our oldest son . . . he goes off to college; that our youngest son . . . he gets better [lifts his hand from the table and drops it back making a sound] and gets . . . you know, gets a little bit better and gets a career, like, even if it’s in, like, a grocery store or something; that we retire together, we do hobbies [prolonged], stuff like that; that we spend our life together and share stuff, and we’re still married. But then the alternate is . . . [pause] would be . . . we’d still be friends [pause] and raise our kids, and still be around while we’re older, and still help them jointly. I may, if that was the case, then I would, obviously, have somebody new, in my life, but that’s the alternate [the same movement and sound] outcome. But both . . . I guess, in both . . . very . . . still, highly positive. You know what I mean? [the same movement and sound] Both A [the same movement and sound] and B [the same movement and sound] are very positive. [the same movement and sound]

Mike later provided even more details with regard to how he sees one aspect of his future, his relationship with his children:

Well, it’s to, basically, help them—especially my oldest, to help him realize what he might be good at. I have a fairly good idea what he might be good at already, and what he thinks he is good at too. You know, development of computers, games, software and stuff
so to encourage him, to try financially support him, to help him in his studies, learning techniques—to, basically, give him encouragement and see him through it, to graduation. And my youngest son, get him the social supports and the community supports to be able to live a life, hmm, somewhat independent, trying to get him into a job and getting him trained, have other people do that. Maybe we don’t know what he’s gonna be able to do, but maybe he’ll work in a grocery store, learning hand over hands, learning these skills, he can have very productive life—extremely. And that’s what my goal is, to help, the best way I can, to get him, to an independent lifestyle and semi, like, independent home; finding different [lifts his hand from the table and drops it back making a sound] techniques to, sort of, maybe, help him have a life . . . I don’t know if he will ever marry—it’s kinda early to say, it’s really early to say because . . . but, maybe, given him every life skill possible, maybe, he can meet somebody that’s something like him, you know, and . . . He’s gonna have a hard, hard battle, yeah, really hard battle. [tongue click] But building [the same movement and sound] confidence in my kids, like I do, [the same movement and sound] and showing them that if things are rough you gotta [the same movement and sound] work harder.

Like Mike, Geoff also included many details in his description of his best possible future:

So what happens is the first book gets published, it does very well, it’s on the New York Times’ best seller list, and, as a result, my second book gets published, and I have a third and a forth one already, and those get published too, they all do well, I end up as an author, I end up doing book tours, I’m able to eventually quit the job—that I’m just about to get into now—and support myself through my writing, and, maybe, doing speaking engagements. Things like that. And I do meet somebody; I don’t know how or when—that’s hard for me to say.

After the prompt, Geoff continued:

I’ve met somebody, whom I love very much, and it’s really the first relationship I’ve ever had where everything is clicking, and I’m learning a lot about myself—because I have a lot of catching up to do, but overall it’s pleasant learning, not painful learning—and we, after the publication of the second book, we move to [San Francisco], we live in a really nice place in the [Haight] and . . . [long pause] Oh, what else? I guess, a lot of my work with, you know . . . my 12-step work, my spiritual practice, all that continues, really, that’s all still there. That’s, sort of, the foundation for everything. [pause] I travel a lot—I love traveling. [long pause] And I’m really happy, and I’m quite amazed that all this has happened to me.

Here is another example of Geoff’s vivid description of his vision of his possible future:

I’m hoping that at some point I will be able to pursue music a little more. And maybe, if I forge a writing career, I may have enough people that, maybe, someday I could put out a
CD or play a show, and maybe fifty people would come and see me—that would be great.

It is important to note that these obvious differences across this study’s participants in the level of detail used to describe their visions of their futures are consistent with the level of detail they provided in their accounts of their past experiences. That is, the participants who provided the most detailed accounts of their futures were the same participants who provided the most elaborate descriptions of their past experiences. This consistency is important because it supports the notion that there are stable individual differences in temporal orientation (Zimbardo & Boyd, 1999), which runs counter to the claims that autistic individuals might have specific difficulties with remembering details from their past (Crane & Goddard, 2008) or thinking about themselves in future (Ozonoff, 1995). Instead, this consistency may suggest stable individual differences in how autistic individuals think of themselves with respect to time: some having access to detailed memories (of either their past experiences or of their future-oriented thinking), others, only to generalizations.

**Level of abstraction.** Level of abstraction was often closely tied to the level of detail and elaborateness—that is, the participants who provided the most detailed accounts of their future tended to be more concrete and less abstract in their accounts—but this was not always the case. Sarah provides the best example. Thus, although she was very concise with regard to her future, her account was far from abstract. Indeed, she was very specific about what she did and did not want, as well as what she wanted, but not at the time of the interview. In fact, she is one of the participants who made the clearest distinction between her goals and her wishes. Thus, she said, she had two goals at the moment: to get a full-time job, which was her priority, and a secondary goal, to live independently. Getting married was not in her thoughts at the moment, but it was a part of her desired future. Likewise, although she wanted to learn to drive, which she included on her wish list, she was careful not to put it on her list of goals saying, “I don’t really see that as a goal right now,” accompanying her remark with several well-founded reasons for exclusion.

Likewise, although Jimmy’s account of his future was also very brief and lacking in details, it was not completely abstract. For example, he was clear that when thinking about his preferred
future, he was not thinking about himself having just any kind of job. As he put it, “When I said ‘have a job that I like,’ it would probably be creating something and being recognized with that.”

Like the degree of elaborateness, the level of abstraction (or the degree of generality vs. specificity; Emmons, 1992) is an important aspect of future orientation, believed to represent a stable individual difference dimension. According to Emmons, having vague and abstract concepts of one’s future is associated with an increased difficulty in monitoring the progress toward achieving one’s goals as well as with slower progress in actually doing so. Moreover, the more specific the goals (and the more specific action plans for their achievements), the more likely it is that they will be achieved (Gollwitzer, 1996). As Oyserman, Bybee, Terry, and Hart-Johnson (2004) argued, more specific goals are both more motivating and more self-regulating (e.g., they are more helpful in maintaining positive affect and behavioral focus than vague and general goals). Nevertheless, Oyserman and her colleagues also emphasized the important self-enhancing role of vague and general goals, which is particularly important at times when things do not go well.

Hope and optimism. When asked to estimate their confidence in the probability of their best possible future actually happening, the participants’ estimates ranged from below 20% (Jimmy) to 80% (Geoff), or perhaps higher (“very confident”; Howard). The estimates of other participants were in the moderately positive range: 60% (Mike, Alan), 66% (Orville), and 70% (Sarah). Thus, all but one participant (Jimmy) were more or less confident that their desired futures would happen.

Nevertheless, it is important to note that although Geoff estimated his confidence very high (80%), his initial answer was, “How confident am I? [long pause] Some days I think it’s possible, other days I’m not so sure. It really goes up and down.” Likewise, although Howard was highly optimistic with regard to the possibility of his desired future actually happening, he was highly pessimistic with respect to one specific area: romantic relationships (which was, incidentally, not within the repertoire of his desired future). For example, one of the relevant exchanges went like this:
L: What if you met a person, a female person, who really understands you and wants to live with you?
H: I don’t look for people, so.
L: Okay, but maybe other people who look for other people find you?
H: It’s not gonna happen.
L: Why not?
H: Because I don’t have interest. I don’t know.

Although Howard’s expressions of both pessimism and optimism may seem contradictory, it should be noted that the same pattern was found in Pierre’s account and that, as previously mentioned, it is well known that people can be optimists in some contexts and pessimists in others (e.g., Cantor et al., 1987).

In contrast, Orville’s remarks throughout the interview were consistent with his estimate (60%). For example, although in 63 years, he only once had a satisfying relationship with another person, he said, “Well, there’s always a possibility, like I tell everybody, another turning point might be happening where [I] am able to find means [. . .] of bonding with somebody.”

Finally, Mike’s uniquely optimistic general outlook on his future deserves special attention. He saw something positive in anything that could possibly happen to him. He hoped that his marriage would work out, “but if not, then I would probably just carry on by myself with somebody else, or . . . but I would always be close—always very close to my children.” As already quoted, Mike considered both possibilities “highly positive.” Accordingly, when asked about the worst possible ending for the book about him, he replied, “I don’t know what that would be, to tell you the truth, I don’t.” And although after giving it some more thought, he came up with the above cited endings (i.e., work- and marriage-related), he did not believe that any of those endings would be really negative. When talking about the work-related negative outcome, he said,

[If] all these other doctors say, “No, you’re wrong,” [refers to the diagnosis of Asperger’s Disorder vs. Delusional Disorder] right? that would be the worst [lifts his hand from the table and drops it back making a sound] possible outcome, but still, even if that happened, it wouldn’t be, that [prolonged] worse because I would still be [prolonged] taken care of medically; I would receive a pension—medical pension.
Likewise, talking about the second negative outcome, getting a divorce, Mike hoped that he will be able to accept it “the way it is”:

But even if that happened [a long pause], I would hope that wouldn’t be, [taps table] that bad [taps table]—it [will] just be, “Well, this is the way it is—you’ve known about it [lifts his hand from the table and drops it back making a sound], it has been going, well, for years.” I don’t feel . . . “Well, okay, I accept that.” I guess that’s . . . you know, I think over time you learn to accept things, so?

Given the previously-mentioned evidence about autistic individuals’ tendency to be pessimistic (e.g., Barnhill & Myles, 2001; Gillberg, 2002), this study’s participants’ self-reported optimism should not be taken for granted. However, as already mentioned, this study’s participants are not unique among autistic individuals in their expressions of optimism. Autobiographical accounts of Sean Barron (Barron & Barron, 1992), Temple Grandin (Grandin & Scariano, 1986), Liane Holliday Willey (1999), Chris Mitchell (2005), and Christopher Slater-Walker (Slater-Walker & Slater-Walker, 2002) provide additional examples.

**The levels of personal agency.** When the participants were asked questions aiming to uncover the level of personal agency (On whom does your future depend?), their answers reflected large ranges of agency. Thus, on the one hand, Jimmy believed that “the only person it depends on is me. [. . .] I feel like it’s all up to me.” Likewise, Alan, who estimated his agency at 80%, said,

It all depends on how you change your behavior, how you . . . if [I] try to blend in, but that’s the hardest thing to do—it’s to try to feel like a normal person, try to do things like a normal [person] and [like] nothing’s wrong, that’s the biggest thing, the hardest thing to do, you know. It’s like that corny song by this boy band called “It’s the hardest thing I’ll ever have to do / to turn around and walk away / pretending I don’t love you.”

Although Orville also believed that his future very much depends on him (also 80%), his view of his agency was somewhat unusual: He believed that his future depends “on me not trying.” He referred to his observation as “the paradox of the situation” and explained as follows:

The less I try to make friends, the more the friends just seem to come out of the woodwork, out of nowhere. Where the more I tried for years to make friends, the urge to make friends just seemed to drive people away cause the less effort I put into it, the more, I guess, the other people perceive me as relaxed, easy going person, and they don’t mind approaching me. But the more I try to be friends with them, urging myself, Yes, you can do it, trying to smile at them, the more they seem to be frightened away from me.
On the other hand, Sarah believed that her future mostly depends on her parents (50%) and only 25% on her, with the remaining 25% being assigned to her friends. Sarah’s estimate was consistent with her whole account in which she many times referred to help she received from her parents. For example, when talking about her goal to get a full-time job, she said, “Right now, we are looking at an agency that might help me find full-time work.” When asked who she meant by we, she said her and her parents.

In summary, most participants believed that their future depends on them. With the exception of 1 participant (Mike), who estimated his contribution to his future at 50%, all other participants’ believed that their future, for the most part, is dependent on them. Their estimates ranged from moderate (65%; Geoff) to very high (80%, Orville and Alan; and 90%, Howard).

**Specific difficulties with future-oriented thinking.** Four participants had some difficulties with future-oriented thinking; they included future-oriented thinking in general (Jimmy), and planning (Geoff and Howard), estimating confidence in the desired future happening (Geoff and Howard), and hypothetical thinking (Alan) in particular. However, Jimmy was the only participant who explicitly admitted having difficulties with future-oriented thinking. Thus, when asked whether he thinks about himself in future, he replied,

> Not too much. I’ve always had a hard time with the future. I’ve never ever been able to think about it. [...] I have trouble thinking ahead, even farther than a week, yeah. And then, I can’t make plans, I just don’t.

Jimmy reiterated his observation in response to another question:

> I’ve envisioned different scenarios, and conversations, and things, but they are always kind of abstract things—they are not wishes, or fantasies, or anything. I don’t really think like that. [...] I have a hard time thinking that far ahead.

Discussing his wish to have more friends and the idea that he could start by meeting people with similar interests (like Pierre and Mike did), Jimmy had an insight about why he might be having so many difficulties with future-oriented thinking:

> Maybe that’s why I don’t think long-term, because it just doesn’t work out, so I just don’t think of [future-orientated ideas] as goals. Like I’ll go online, I’ll look for groups, won’t
see any, and that would be the end of that. [...] I have trouble maintaining motivation, like, I might set a goal “Okay, I wanna join this group,” or whatever, but I can’t maintain that—it just fades. No matter what it is, but it just kind of goes away.

Like Jimmy, Geoff also said that he does not have a tendency to set long-term goals and that he prefers to live “one day at a time.” However, unlike Jimmy, he did not consider his approach to the future a deficiency but rather a matter of preference:

I don’t tend to think in terms of five-year plans. [...] I try to live one day at a time, really, yeah. So, yeah, I don’t tend to think of, In 5 years I will be, you know . . . If my goal is here, and I’m now here, in 5 years, I will be there. I don’t think that way at all. [...] I don’t tend to think that way. And I don’t tend to set goals, except with specific projects, like writing a book, which is a manageable thing where you can create a goal, but other things, no. [...] I tend to think the next step ahead, and I might say, If it doesn’t work, oh, then I have ten options. And I’ll deal with the ten options if I get there. That’s how I tend to do it.

Geoff, as well as Howard, at least initially, also felt uncomfortable answering questions about their level of confidence in their desired future materializing. For example, Geoff said

I guess, I’ve seen enough in my life already to realize that life takes some very unexpected twists and turns, so there are all sorts of things that might well happen that I can’t possibly envision right now. [...] I don’t really know. I’m really having trouble answering this question in this way. Like, I don’t tend to think in terms of like statistical probabilities at all. [...] It’s hard to quantify . . . It could be anything, you know, I could, you know, I could walk across a street and get hit by a bus and be paralyzed. Anything. Anything could happen.

Howard expressed the same sentiment in his answer to the same question: “You never know the future—one day at the time.” Although Alan had the same tendency as Geoff and Howard to think in terms of anything could happen, you never know, unlike them, after I probed his initial answers—which usually started with “it’s impossible to know for sure,” “we don’t know,” “you never know”—by emphasizing that I was interested in his vision and not in what will actually happen, he was able to change his mindset and provide different answers, which were reviewed above. Here is one of his initial replies about his desired future:

You never know. [I] could be drinking or gaining too much weight or anything like that. I could even end [up] getting a disease like cancer or something, but we don’t know, we could be . . . Somebody could kill me, somebody could murder me—we don’t know for certain. [...] [I could go to a] retirement home, you know, like [in that], depressing
movie, *The Notebook*, there, you know. We don’t know what it would be like for autistic people—what they are going to be like if they have similar disabilities when they are older, you know.

However, Alan seemed unable to think in terms of counterfactuals. Thus when asked about living in another world—a better one—he answered, “I have no idea. It’s very hard to say.” (I did not probe his answer further.)

This study’s participants’ difficulties with future-oriented thinking, and planning in particular, are consistent with literature on executive function (Ozonoff, 1995) as well as with a recent report from a psychotherapy perspective (Bliss & Edmonds, 2008), which indicated that people with Asperger syndrome found questions about their preferred future “really difficult” “probably about half of the time” (p. 74). However, it should be noted that problems with future-oriented thinking are not unique to autistic individuals and that they are also associated with individuals with anxiety and mood disorders (MacLeod & Byrne, 1996). It is then interesting that the participant who exhibited the most difficulty with future-oriented thinking was also diagnosed with both anxiety and mood disorders. As Jimmy himself pointed out, the lack of future orientation may also reflect a lack of past positive experiences with planning. Alternatively, as previously suggested, it may also reflect a lack of knowledge about ways that could lead to positive outcomes.

It is interesting that in addition to Jimmy and Geoff, 3 other participants (Orville, as quoted above, Sarah and Howard) also mentioned a “one-day-at-a-time” approach to the future, and, as already discussed, that also seemed to be Pierre’s mode of living (although he did not use the phrase). Thus, Howard said, “I enjoy life, I take it every day the way it is. I take everyday life one day at a time,” and “You never know the future—one day at a time.”

In psychological literature, the focus on the present is recognized as a specific personality style (Zimbardo & Boyd, 1999) associated with more avoidant coping strategies as well as with less positive adaptation (Epel, Bandura, & Zimbardo, 1999). For example, a predominantly present orientation is associated with more substance abuse (Keough, Zimbardo, & Boyd, 1999) and longer durations of homelessness (Epel et al., 1999). However, although Zimbardo and Boyd considered present-oriented thinking style as undesirable in Western society—they referred to it
as “[temporal perspective] discordance” and suggested that “those high on present [temporal perspective] may be ‘speaking a present-oriented dialect’ in a setting that recognizes only the meaning and value of future-oriented language” (p. 1285)—a present orientation is also found to be beneficial in a variety of life situations. For example, it is advantageous, even necessary, during acute crises as it facilitates the search for temporary solutions (Epel et al., 1999). Moreover, a one-day-at-a-time slogan plays an integral role in the most popular alcoholism self-help treatment (Alcoholics Anonymous; Valverde & White-Mair, 1999), with which Geoff is very familiar through his involvement with a similar group. However, although a “present-oriented dialect” was predominant in several participants’ accounts, it is not clear how much it contributed to their short- or long-term adaptation.

9.3.4.1.2 Summary

The participants were both similar and dissimilar to each other in their future-oriented thinking. Most similarities were in the repertoire of the participants’ desired and undesired futures. Their visions of the desired futures were consistent with both the autism literature and the literature on typical development: they desired what other people, both autistic and nonautistic, desire: adequate social relationships, jobs, and living arrangements, as well as the opportunity for adequate leisure, learning, and other personally relevant activities. However, the wish lists of most of the participants included one unique item (not found on wish lists of non-autistic people): a wish to be understood and accepted. This wish is particularly important because it sends a clear message as to what we as a society should do to help autistic individuals improve their lives. It is also interesting that, contrary to the prevailing view of autistic people as “extreme[ly] egocentric” (Gillberg et al., 2001, p. 64) and lacking a concern for others, most of this study’s participants showed an interest in the welfare of other people and included them in their most important wishes.

Finally, in line with current autism literature, most participants showed at least some difficulty with future-oriented thinking, with goal setting and planning in particular. However, in contrast to what would be expected from the literature, the participants also showed a lot of variation in all aspects of future-orientated thinking that were considered, from the degree of thinking about
the future to the level of expressed agency, which is more consistent with the view of future-oriented thinking as an individual difference in personality (Zimbardo & Boyd, 1999) than with a view of a specific deficit in future-oriented thinking.

9.3.4.1.2.1 Better Worlds of Other Participants

All participants except Alan revealed their visions of a better world. For 3 participants (Mike, Orville, and Jimmy), an ideal world would be a world where autistic, as well as all other people would be *accepted* for “who they are” and where even things would be seen “as they are” (Orville). More specifically, in Mike’s “utopia,” “everybody [. . .] accepted everybody [. . .] [and] they accepted you for who you were,” and everybody would also be *fair* to everybody—“all the time.” In Jimmy’s perfect world, people would be “more friendly [and] non-judgmental,” whereas in Orville’s, in addition to autistic individuals’ acceptance, people would see things “as they are,” that is, without looking at them through their market value:

*I’d* like to live in a world where *numerical values do not dictate in any way* human endeavors at all. That is, there’s no such a thing as *economics* to dictate people’s lives. I’ve been asking all my life, “*Why do we have this concept of payment or value systems to basis of numbers put* on everything we do and every object out there? Why does this pen have to have a numerical value attached to it? It makes me think of a cartoon I saw once where this real estate agent is showing this property to this couple and this lady comments on, “What a beautiful tree that is in front of the property!” and is admiring how wonderful it is, and the real estate agent answers her by saying, “Yes, that tree adds about 87 dollars and 42 cents to the value of the property.” Well, it’s *that* aspect of life that I’m afraid we’re becoming so *overburdened* with in the world today that I’m praying that, even if it’s by evolution, we *gradually* move away from that to the point where we can begin [taps] to look upon things as they *are* but without these *numerical* values added to them.27

Sarah’s perfect world would be “a world that has world peace and no violence and pretty much what I said about my three wishes” [which also included everyone having their own home and having enough food].

27 Orville added that economics for him is “almost like a god of our times—god with a small g,” and that “this god of economics [. . .] seem[s] to be thousand time more powerful than any religious book I know of.”
In Geoff’s ideal world, “how to be social” would be an important component of schools’ curriculums:

in my ideal world, children would be explicitly taught when they were young that school was to learn how to be social. That someone would actually tell you this. And that there would be classes for those of us who were, you know, needed remedial work in that area.

In Geoff’s utopia, there would also be no dress code:

I would love to live in a world where [pause] people can go to work dressed any way they like. [. . .] If you are a justice of the peace, and you wanna show up in a torn t-shirt and ripped jeans, that’s fine. If I were prime minister, that would be the first law I’d pass.

In his usual joking style, Howard’s initial response was, “I would choose to live on Mars.” Asked why, he responded, “Because I would be the only person [there].” His more serious version of a perfect world was, “A life without autism—with a million dollars.”

9.3.4.1.2.1.1 Interpretive Summary

Although most participants expressed individual visions of a better world, 3 participants reiterated the same view, that is, of a world where autistic people were better accepted. It is particularly interesting that most participants’ visions of a better world reflected their concerns for others and that only 1 participant’s (Howard) vision concerned only him (i.e., not having autism and having a million dollars). Although most participants’ visions reflected at least some of their current needs or preferences from which they could benefit (e.g., more acceptance, no dress code, no market economy), the participants clearly believed (and most explicitly mentioned it) that others would also benefit from living in such worlds. However, 2 participants’ (Sarah and Geoff’s) better worlds had no immediate benefit for themselves whatsoever. Moreover, although broadly viewed, one could see that Sarah could benefit from living in a world of peace, without violence, and with everyone’s basic needs being met, Geoff’s vision of a world where schooling would include learning social skills—although clearly informed by his own experience—would not benefit him in any way. Such other-oriented visions are contrary to the traditional view of autistic individuals as self-focused and unconcerned for others (e.g., Baron-Cohen, 2005; de Vignemont & Frith, 2008). Such a view was recently summarized by de Vignemont and Frith as
follows: “Individuals with Asperger syndrome display extreme egocentrism [. . . .] Their social world is self-focused” (p. 277), whereas Baron-Cohen (2005) wrote, “People on the autistic spectrum, even the high functioning individuals, such as those with Asperger Syndrome (AS), are essentially wholly focused on their own [self]” (p. 178).

Taken together, participants’ visions of a better world were visions of a more just world, which is in accord with other autobiographical accounts (e.g., McMullen, 2000)—as well as with the observations made by others who got to know autistic individuals well (e.g., Jacobs, 2006), including occasional clinician (e.g., Attwood, 2006) and researcher (e.g., Baron-Cohen, 2005)—that autistic individuals have a keen sense of justice. It is interesting that Baron-Cohen, in the same article (in fact, in the same paragraph cited above) in which he claimed that autistic individuals are totally focused on themselves, observed that autistic individuals “typically have a strong sense of justice, for others as well as for the self” (p. 178). Indeed, this was a concluding sentence of his article entitled *Autism*—“*Autos*”: Literally, a total focus on the self? Although it appears that the title’s question mark owes to this observation about autistic individuals’ “strong sense of justice,” this observation—curiously enough—did not make Baron-Cohen change his mind about autistic individuals’ total focus on the self because he believes that this sense is due to autistic individuals’ “good logic” (p. 178) and not self-oriented emotions such as empathy, which he (I believe erroneously) believes is the only true source of focus on others. I will return to this issue later in the section on the participants’ understanding of their emotions.

9.3.4.1.2.2 The Other Participants’ Recommendations

Each participant made at least one recommendation for making the world a better place for autistic individuals; Orville made the most (i.e., five) recommendations. Five participants’ (Sarah, Howard, Mike, Orville, and Geoff’s) recommendations concerned better understanding from general public, experts, and/or parents. For example, Sarah’s recommendation was “for people to be aware of autism, like, get information about it,” whereas Howard recommended, “Everybody understands autism, [that] it’s not a secret disability that nobody has heard of.” Likewise, Mike suggested “more education” and “more understanding” of people with Asperger Syndrome in particular because their difficulties are invisible. As he put it,
Aspies [people with Asperger syndrome] are difficult to distinguish [. . .] from their peers [. . .] and people’ll say [. . .], “He walks, he talks, he went to school, he’s intelligent [. . .]—What’s his problem? I don’t get it”. Asperger’s are really tough one, REALLY TOUGH, okay, to explain to people.

Geoff recommended a different conceptualization of autism—as a human variation, not a flaw that needs cure:

The first thing I would recommend is an understanding that we’re different, as opposed to being flawed, and that we don’t need to be cured. Our way of looking at things is different, and it’s equally valid and [long pause]. I guess, I sort of feel that autistic people can learn something from neurotypical people, and neurotypical people can learn something from us.

Similarly, Orville recommended better education for all people with regard to what normality is. For him, it involves a multitude and not a singular normalcy as currently held by many people who believe “Whatever is normal to them should be the rule of law for everybody on planet Earth: ‘You have to be normal. You can’t be any other way.’” Orville would like it if he could somehow help people “begin to accept that everything in the world cannot be cloned into one thing—‘normal.’”

Two participants’ (Alan and Jimmy’s) recommendations concerned better experts’ understanding of autism that would lead to better support for autistic individuals. Thus, Alan suggested more investment into experts’ understanding of “how to help [autistic individuals] and make them feel better, and try to make them fit in more, and try to make them what they are.” Likewise, Jimmy recommended “just better understanding [. . .] and better support,” including earlier identification of autism:

More early testing, probably in school, to try to discover these kinds of things early on and treat them sooner, you know, instead of putting people in jail; trying to understand what made them do what they did in the first place, sort of attacking problems from that angle instead of backwards.

Jimmy also said that if he were identified earlier, his life could have been different because he “would have known enough to not get into the restaurant business.”
One participant (Orville) recommended better understanding of parents of autistic individuals about autism as a life-long condition and “not a childhood disorder,"

As though once a child gets up to 20, 30, he should be okay with all this ABA [Applied Behavior Analysis; a popular but controversial behavioral treatment] stuff and everything else like that, as though [at] 21 all of a sudden everything would disappear: he’ll have a good job, he’ll have a life of his own, a family, and everything. Well, I’m sorry, but that is, again, a dream world [laughs], at least in his lifetime—not that it won’t happen a thousand years from now. [. . .] So it’s that part of it when a person in their 20s wonders what to do or how to express themselves, I just wish there is better understanding out there.

One participant (Orville) made two recommendations concerning interventions for autistic individuals. First, he proposed more teachers’ involvement in socialization of autistic students. He suggested teachers provide opportunities for autistic students to gain positive social experiences without trying to change them, for example, by allowing other students to get to know their autistic classmates better. He gave the following hypothetical example:

Say, there is an autistic boy in a classroom, and teacher sees that the other kids don’t understand a kid, and he hardly ever looks at anybody, and he’s just off by himself all the time, maybe staring, or doing whatever he does with arms. [. . .] That’s the time, I’d say, for the teacher to come in and, not just explain his condition to the rest of the class, but have more interaction. Not that they are trying to change him saying to the kids—his name is Peter—“Come on Peter, can’t you play with these kids more?”—that’s attempted change, but almost the opposite, saying to the kids, “Well, Peter has tried to come and play with you, but how about we reverse it? Peter loves to sit there and do whatever he does, why can’t the rest of you if not all at the same [time], but, say 3, come over and share Peter’s experience with [him]?” That’s what I would like to see.

Second, Orville recommended more investment into finding “better communication for those people who have a lot more difficulty in speaking and communicating, even beyond Facilitated Communication [a controversial communication intervention for non-verbal autistic individuals] and things like that—to find a way that they can begin to say words slowly.”

One participant (Jimmy) also recommended better general support for autistic individuals, by which he meant “making things less complicated,” like,
life in general. Having things a lot simpler [. . .]; things, like, where everyone is kinda
guaranteed a home, security, that kinda thing. Where we as a society, sort of, take care of
each other more, instead of everybody [being] there for themselves.

Finally, although better acceptance was implied in most participants’ suggestions regarding
better understanding, Orville specifically recommended “more acceptance upfront,” about which
he also talked throughout the interview.

9.3.4.1.2.2.1 Interpretive Summary

Autistic individuals’ recommendations involved better education for all, including general
public, experts, teachers, and parents, as well as earlier identification of autism, better treatment
options, and more acceptance of autistic individuals. Some of these recommendations, such as
erlier identification and better treatment options, are identical to those made by autism experts,
whereas others, such as more understanding, acceptance, and better support, are unique to them
and autism advocates. The recommendation for better understanding by experts echoed other
autistic individuals’ frequent claims that they are largely misunderstood by them (e.g., Holliday
Willey, 1999; Jackson, 2002; Schneider, 1999; Sinclair, 1992; Williams, 1996a; for a review, see
Vuletic et al., 2005).

Given autistic individuals’ presupposed lack of concern for others, and their self-focus (e.g.,
Baron-Cohen, 2005), it was particularly interesting that, as was the case with the participants’
conceptions of a better world, their recommendations concerned all autistic individuals including
those of different ages and abilities than theirs.

9.3.5 Pierre’s Self-Understanding and Meaning Making

Pierre’s interviews and diaries are immensely interesting sources for analysis of his self-
understanding. Although several of its aspects could be viewed as possibly problematic, other
aspects appear rather sophisticated. Before discussing strengths and weaknesses of Pierre’s self-
understanding, I address the issue of the reliability of Pierre’s self-report.
9.3.5.1 On the reliability of Pierre’s Self-Report

Given the still-prevailing mistrust in autistic individuals’ abilities to provide self-report and to self-reflect (e.g., Frith, 2003; Hobson et al., 2006), it is important to make a note about the reliability of Pierre’s self-report. To this end I examined the concordance between different statements Pierre provided on related topics he provided at different time points during the interview and in his diaries.

In my view, only one set of Pierre’s statements from the entire interview could potentially be judged as contradictory. The statements in question pertain, on the one hand, to his tendency to get discouraged easily and, on the other hand, to his optimism about his future. Although at first glance the two stances may seem incompatible, they could, as previously mentioned, easily be explained with reference to the specific contexts in which they apply: although Pierre is (in general) optimistic about the future, he is pessimistic (i.e., gets discouraged easily) when it comes to specific types of situations such as dating.

It should also be noted that Pierre provided similar descriptions of the same events in response to different questions and that his interview self-statements are consistent with what he wrote in his diaries. Given Pierre’s belief that his family would agree with his self-descriptions—which was at least partly confirmed in my informal meeting with them—the fact that he could not think of anybody who would describe him in other terms than he did, and the fact that his self-descriptions were consistent with my impressions of him, it is reasonable to suggest that we can accept Pierre’s self-report as reliable.

Likewise, there were no major contradictions among other participants self-reports.

9.3.5.2 Weaknesses of Pierre’s Self-Understanding

Several aspects of Pierre’s self-reporting appear to be problematic—at least at first glance. They include difficulties with talking about his self-reflections in general and about his feelings and autobiographical memories in particular.
Self-evaluation. Despite Pierre’s reasonably good and reliable self-report, the process of producing it was rather laborious. Although Pierre did not have any difficulties providing factual information about his life, he hesitated when answering questions aiming at the evaluation of his experiences. The fact that Pierre does not have ready-made answers about himself could be taken to mean that, perhaps, he does not engage in much self-reflection and/or that he is not sure of his self-understanding. “I don’t know” and “It’s hard to say” were his initial answers to 39 questions (20 and 19 respectively). For example, his answer to the first non-factual interview question (which asked for his self-description) was, “I don’t know what to say, really.” In addition, he qualified many of his statements by adding a “maybe” (42 times) or “I guess” (166 times). Of course, he is sometimes using I guess as a pause filler. However, Pierre’s use of I guess and other uncertainty words in his diaries, when making rare self-reflective entries, provides some support for the interpretation that at least some of these qualifying words could be a true expression of his uncertainty in his self-knowledge. For example, referring to his first attempt at Internet dating, he wrote in his diary: “I revealed too much about myself because I didn’t know [emphasis added] what else to say. I guess [emphasis added] I shouldn’t have revealed I have ‘geek syndrome.’ But would it have been better to say nothing?” (January 6, 2003). In another entry (more than 5 years later), he wrote, “[I] saw something on the net about how you should start a dating profile by saying what’s most compelling about you. I’ve been wondering [emphasis added] what’s most compelling about me. (My ideals?)” (March 16, 2008). Pierre’s difficulty with answering questions that required self-reflection was also evident as he would often take long and frequent pauses and would sometimes also close his eyes so hard that his whole face would become distorted.

Although Pierre’s hesitant manner of answering non-factual personal questions may be taken by some as an indicator of his difficulty with self-reflection, I believe that his manner could be

28 Here are some examples of Pierre’s answers which he prefaced with “I guess”: “I guess you can say I am intellectual.” “I guess, I am an idealist.” “I guess, maybe I seem remote sometimes.” “I guess, [one of my strengths is] my willingness to think outside the box—imagination.” “I guess, another weakness of mine is that I get discouraged easily.” “I guess I like my being imaginative.” “I guess I sometimes feel emotionally cold.” “I guess, I would like to be more independent.” “I guess I like being different.” “I guess I like being logical.” “I guess, I can be good at analyzing things.” “I guess I feel ashamed of it.” “I guess, maybe I could write.” “I guess I was disappointed in my parents.”
better interpreted as a specific cognitive style, or cognitive attitude toward the very possibility of really knowing things about oneself—as opposed to guessing—which Pepper (1942) termed utter skepticism. In fact, if we consider Pierre’s interview as a whole, it becomes clear that his answering style is consistent with being cautious about giving definitive answers and leaving an impression of “knowing” things that he may feel are more like momentary intuitions, the result of feelings—not reasoning—more guesses than knowledge. Being a logical thinker, Pierre must be aware that personal knowledge is not acquired by logic, and it is reasonable to assume that he feels uncomfortable with giving subjective statements—those not based on memory of facts or logic—status of knowledge (that is, not prefacing them by “I guess”). Therefore, it seems to me that Pierre’s reluctance to answer certain kinds of personal questions may actually stem from his sophisticated philosophical stance on knowledge in general, not from self-ignorance. This skeptical epistemological stance is best reflected in his answer to a question about his most disappointing life experiences, to which he replied “I just don’t know. To me, disappointed isn’t something you can, like, measure.” This stance is also reflected in his explicit concern with the accuracy of his answers. For example, it was important for him to correct the interview transcript by adding the name of the book on autism he read, which he could not remember during the interview but recalled later.

If this interpretation is valid, Pierre would not be alone in believing that self-knowledge is not like historical (encyclopedic or factual) knowledge, and the best one can do is guess. In fact, there is a whole philosophical tradition holding the view of self-knowledge being unattainable in principle (e.g., Nietzsche, 1887/1967; Sartre, 1956; for discussions of this issue, see Hamlyn, 1983; Jopling, 2000). For example, Nietzsche famously wrote,

> We are unknown to ourselves . . . . We are necessarily strangers to ourselves, we do not comprehend ourselves, we have to misunderstand ourselves, for us the law “Each is furthest from himself” applies to all eternity—we are not “men of knowledge” with respect to ourselves. (p. 15)

Likewise, after narrating and reflecting on his life as best as he could, Sartre (1964/1981) acknowledged his inability to make sense of many aspects of himself, and, near the end of his autobiography, he transferred the task to the reader: “So try to figure it out. As for me, I can’t” (p. 254). Following Freud, other psychologists also admitted the impossibility of perfect self-
understanding. For example, Claparède (1930), at the end of his autobiographical essay, admitted:

I have come to the end of my reminiscences. What interest they can have for anyone, I hardly know save for myself, to whom they have shown how difficult it is, even for a psychologist, to have a clear vision of oneself. (p. 14)

Moreover, psychological research supports claims about the difficulty of fully understanding oneself and about the problematic and uncertain nature of self-knowledge (for a recent review of this issue, see T. D. Wilson & Dunn, 2004; for a historical review, see Baumeister, 1987). Yet, although these views and findings support Pierre’s philosophical stance on the epistemological status of self-knowledge (Hamlyn, 1983, and others, argued that it is inappropriate to talk about self-knowledge and that instead we should talk about beliefs about oneself), they are overly pedantic and absolutistic for everyday purposes. As the psychological literature suggests, self-understanding need not be complete to deserve a knowledge label (Neisser, 1988, talked about five kinds of self-knowledge), nor does it need to be complete or accurate to be useful (S. E. Taylor & Brown, 1988; T. D. Wilson & Dunn, 2004).

Nevertheless, some may argue that one of Pierre’s responses—the probing of his answer to “What could never change about you?” to which he replied, “It is hard to say, I actually think about that a little”—could be taken as an acknowledgment of his non-engagement in self-reflection. However, this is not necessarily so. First, several non-autistic participants in the pilot study had similar reactions to the same question. Second, this was Pierre’s reply to a follow-up question (Is there anything else?) and not his initial response to the question.

Although when taken together, Pierre’s answers suggest that he may know more about the world than about himself, there is also evidence that shows that Pierre may know more about himself than he is willing—or able—to share. For example, when I confronted him about his many “it’s hard to say” answers in our follow-up interview, he said, “I find it hard to talk about myself,” thus supporting my cautionary note about equating what he said with what he thinks and knows about himself. Indeed, Pierre was even uneasy talking about his talents and did not mention many of them—I only learned of them by reading his diary. For example, he never mentioned
that he is a (former) member of Mensa, plays piano, has an excellent musical memory, and can calculate big prime numbers in his head by a method he invented. Not sharing these exceptionalities is consistent with his assertion that “Self-promotion isn’t one of my skills,” as well as his statement about it being hard to talk about himself. (Not sharing these abilities also demonstrates Pierre’s humility.)

In addition to the above-argued interpretation of Pierre’s difficulties with self-understanding as a specific cognitive style, there are some other non-autism related interpretations. Another possible contributor to his relative lack of engagement in self-reflection could be his gender. Research has suggested that men in general are less likely to engage in self-reflection than women (Csank & Conway, 2004). Yet, psychoanalytically oriented scholars would argue that it is an unconscious fear of the emotional pain that prevents Pierre from self-explorations (J. L. Singer, 1990). These scholars would argue that it may be too painful for Pierre to explore himself. I return to these interpretations after I consider other participants’ self-understanding.

**Feelings.** Pierre rarely answered questions about his feelings using specific emotion words. For example, when asked how he felt when he lived away from his parents, he replied, “Well, it was a time of flux, as they say—it was a time of new experiences.” When he answered using emotion words, these words tended to be very general (e.g., like or dislike). For example, when asked how he felt when he was bullied, Pierre said, “I didn’t like being reminded that I was the baby of the class.” Thus, although during the interview Pierre used 31 different emotion words (see Appendix E), many of these terms refer only to valence (e.g., feeling bad, liking, dislike, satisfaction, being troubled) or an absence of feelings (e.g., “not proud,” not interested, emotionally cold) as opposed to specific feelings (e.g., anger, shame, humiliation, happiness, love, and regret). This pattern is somewhat surprising given Pierre’s life-long love for reading fiction and watching movies. As Oatley (2009) argued, fiction is a kind of simulation of selves in a world; consequently, reading fiction improves people’s understanding of their own emotions, as well as themselves. Importantly, Pierre is aware of his difficulty with understanding his emotions. For example, he acknowledged that his “trouble” with answering the question how are

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29 All Mensa members score “within the upper two percent of the general population on an approved intelligence test that has been properly administered and supervised” (Mensa International, 2000).
Pierre’s difficulty with describing his emotions fits well with the autism literature, which has long established autistic individuals’ difficulties with emotional processing (Asperger, 1944/1991; Attwood, 2006; Kanner, 1943). As Attwood (2006) put it, the “inner world of emotions appears to be uncharted territory for people with Asperger’s syndrome” (p. 130). Moreover, research has demonstrated autistic individuals’ difficulties with both identifying and describing emotions (Begeer et al., 2008; Hill et al., 2004). However, although these difficulties are thought to be an integral part of autism, they are not specific to it. The inability to describe emotions has been termed alexithymia (i.e., having “no words for feelings”) and has been found in a range of psychiatric disorders (G. J. Taylor, 1984). For example, when they are upset, alexithymic individuals have difficulties telling whether they are sad, frightened, or angry. The same is true for at least some autistic individuals (Hill et al., 2004). As Wendy Lawson (2000) wrote, “I find emotions interchangeable and confusing. Growing up, I was not able to distinguish between anger, fear, anxiety, frustration or disappointment” (p. 8). However, having difficulties with labeling emotional experiences is also common among non-autistic and non-alexithymic individuals. As Scherer (2005) suggested, many ordinary individuals who participate in emotion research “who do not normally attempt to label and communicate their emotional responses, may have problems coming up with appropriate labels” (p. 712).

Yet, to be fair to Pierre, although his reply to the question about his feelings in response to being bullied did not include a specific feeling word, he did spontaneously say that he was angry while he was describing the bullying events. It should also be noted that I did not specifically probe Pierre’s understanding of his emotions and that this analysis is based on the content analysis of the interviews. Moreover, when considering Pierre’s understanding of his feelings, it is important to keep in mind that our conversation was about his remembering the feelings he had more than 30 years ago and not his current feelings. In addition, Hacking (2009b) has recently argued that the psychological “inside” of autistic individuals may not correspond to that of typical individuals and that autistic individuals might need to invent new words to describe them. (However, as already mentioned in the introduction, Donna Williams, 1998, from the first-person perspective, argued that the mental processes of autistic individuals differ only in “volume” [i.e.,
quantity] and not in quality.) From this perspective then, Pierre’s relative difficulty with using emotion words may stem from the lack of their correspondence with his feelings. Finally, the most parsimonious explanation for Pierre not answering my questions about how he felt (at the time of the events he was describing) with reference to his feelings but instead with a description of his thoughts is that the question did not specifically ask how he emotionally felt. Although the word feel is used in psychology to refer to subjectively felt emotional or sensory experiences, this is not so in everyday English where to feel is also used to mean believe and think (Soanes & Stevenson, 2005). However, despite Pierre’s problematic answers to direct questions about his feelings, my impression was that his working emotion lexicon was much greater but that he was not used to talking about his feelings and could not easily retrieve words when asked. Some support for this interpretation could be found in his several descriptions of situations from books and films involving characters that felt similarly to how he did.

**Autobiographical memory.** Another area of difficulty for Pierre was, as already mentioned, his inability (which sometimes also looked like an unwillingness or avoidance) to remember specific experiences in support of his self-statements. For example, he suggested that he does not think much about decisions he could have made (“the roads not taken”) and that he worries about “the roads taken” by trying to “figure out what to do next.” However, he could not provide an example for this. Similarly, he could not “single out particular experiences” from which he learned important life lessons. As he put it, “I feel like I’m always learning things—it’s hard to single things out.”

This pattern of knowing one’s traits without being able to remember specific events involving them is consistent with research evidence that suggests that autistic individuals have difficulties with retrieving memories of experiences on which self-knowledge is based (S. B. Klein, Chan, & Loftus, 1999). In addition, as already mentioned, this pattern is also consistent with research evidence suggesting that autistic individuals have a deficient autobiographical memory with regard to its specificity (Crane & Goddard, 2008). However, Pierre’s difficulty with remembering specific events also fits well with the research on depressed and traumatized

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30 According to the Oxford Dictionary of English (Soanes & Stevenson, 2005), one of the meanings of the word feel is “have a belief or impression, especially without an identifiable reason” (i.e., “hold an opinion”).
Nevertheless, Pierre had no difficulty providing vivid, detailed, and emotional descriptions of personally important autobiographical memories, such as those related to his experiences of being bullied. One way to explain this discrepancy is that in his effort to make meaning of his bullying experiences Pierre perhaps replayed his traumatic events many times in his memory so that he now has no problem retrieving them at will, which is not the case with other events that were significant but did not require prolonged efforts to their understanding.

**Self-interest.** Given all these difficulties with talking about himself, one may ask, why Pierre wanted to participate in research that required exactly doing things he did not like. When I, in a follow up interview asked Pierre this question, he said, “It’s fun to be analyzed. [. . .] I like being analyzed. As all baby-boomers, I am fascinated with myself. I am self-centered.” However, from the third-person perspective, Pierre’s fascination with himself appears to be only a half-fascination. That is, he likes being analyzed, but he does not like to engage in self-analysis nor does he like to read psychological literature—which he could possibly use to try to better understand himself. Not only did he not read much about autism when he got diagnosed, but he also never read any psychological books. Given his love of learning and reading, I find this surprising. Although he initially said that he reads “anything” (and his diaries corroborate that), he later corrected himself by adding, “except psychology.” Why would this be so?

When, in a follow-up interview, I asked Pierre this question, he said, “I assume books on psychology are boring. They are abstract.” However, when I asked him whether he would agree with my proposition that his not reading much about autism could be viewed as avoiding learning about himself, he said, “It’s possible.” Although avoidance of knowing could be considered a coping strategy (Carver, Scheier & Weintraub, 1989), this is, however, as previously mentioned, not a typical strategy of high functioning autistic individuals who, based on anecdotal evidence, in most cases try to learn as much as possible about autism as well as about other psychological or neuroscientific issues that they think could be useful for bettering their understanding of themselves (e.g., Gerland, 1997; Grandin & Scariano, 1986; D. Williams, 1992).
Moreover, Pierre’s fascination with himself seems to apply only to those aspects of himself that he likes. At our last meeting, which occurred at the time I was concluding writing about him, when I mentioned that I would soon send him the report I made about him (as was promised in the consent form), he said that he was not “in a hurry” to read it, which is the same expression he used to describe his reaction to getting diagnosed with autism (“I wasn’t in a hurry to read about it”). After I expressed my surprise at this contradiction—he had just told me that he enjoys being analyzed—he said that he did not know how he would react if I wrote something he did not like, showing once again his inclination towards using the avoidance coping strategy (Folkman & Moskowitz, 2004).

9.3.5.3 Strengths of Pierre’s Self-Understanding

Pierre was able to identify both his important personal characteristics as well as the specific points in his life that contributed the most to becoming the person he is now. He thus demonstrated that he is able to think about himself and his life and that he is able to find what is extraordinary about him and about his life. Pierre clearly did not choose just any experiences from his life, but exactly those that had the greatest impact on it—as he sees it. In other words, Pierre was able to take a stand with regard to what was important in his life and what was less so, what was good and what was not. In doing so, he, in essence, chose his identity, which C. Taylor (1989) defined as “the horizon within which I am capable of taking a stand” (p. 27).

Moreover, despite the time Pierre took to answer most of the questions about himself, many of his answers could be interpreted as being at an advanced level of self-understanding. This was evident from the very beginning of the interview when he said that being diagnosed with autism does not actually explain him as a person and that autism is “just one part of [him].” Likewise, his remark about disappointment not being measurable, and his reluctance to assign quantitative values to the importance of his experiences, may also be interpreted not as an indicator of poor self-understanding—as it appears at the first glance—but as an expression of a more sophisticated self-understanding that takes self-evaluation seriously (as opposed to an arbitrary assignment of a value to an experience without much reflection).
Admittedly, not everybody would agree that the above-mentioned examples are markers of an advanced self-understanding. However, Pierre’s meaning making of his important life experiences is a much clearer indicator of such understanding. For example, Pierre said that the importance of his bullying experiences for becoming the person he is now is that “I felt I was in a difficult situation—one that I couldn't handle so well.” It is clear that in order to make this conclusion one must have a clear concept of oneself before and after the experience, as well as the ability to compare the two concepts and extract the difference. The same is true for other meanings he constructed, such as the influence of his experiences with his parents on his trust of other people.

Pierre’s description of how he felt when he needed to make a difficult (no-win) decision between listening to his parents and not going to school—which would have as a consequence increased bullying the day after—and going to school against his parents’ will knowing that “when I didn't do it their way [I] regretted it,” also suggests that his self-understanding might have been rather advanced even when he was younger. He said, “I felt really stupid, like, I knew what the consequences would be . . . I took the path of least resistance—and I paid the consequences.” Taken together, these remarks suggest Pierre’s full awareness of both the choices and their consequences, as well as the reasoning behind his choice.

What is even more remarkable is that based on what Pierre said regarding not talking to others about his life experiences, it appears that Pierre constructed these meanings all by himself, which is contradictory to the widely accepted tenet about the crucial role of others for children’s meaning making of their life experiences, story-telling, and other related aspects of self-understanding, as previously reviewed.

**In summary.** Pierre appeared to have some difficulties with at least some aspects of his self-understanding, such as reporting about some of his experiences, feelings and autobiographical memories in particular, and self-reflecting on some of his experiences. When taken in isolation, these difficulties are congruent with academic thinking about self-understanding in autism, which suggests that autistic individuals’ self-understanding is impaired (Baron-Cohen, 1989b; Frith & Happé, 1999; Hobson et al., 2006). However, this conclusion would not be valid when
we consider everything that Pierre said and wrote about himself. Although Pierre appeared uncertain of his self-knowledge, his answers were well supported, and they held well together in the context of everything he said and wrote about himself. Moreover, some aspects of his self-understanding, the meaning making of some of his life experiences in particular, appeared to be at an advanced level. (As already discussed, this was not true for Pierre’s meaning making of his bullying experiences, which, given their traumatic nature, most likely required professional help.) Finally, it is difficult to know whether and how much Pierre’s difficulties with self-understanding are related to autism and how much to the lack of practice of talking about his psychological life.

9.3.5.3.1 Other Participants

Because other participants’ self-descriptions and autobiographical memories were previously reviewed in some detail, to avoid repetition, in this section I only review these participants’ understanding of their emotions, and make general remarks about their self-understanding.

9.3.5.3.1.1 Understanding Emotions

In this section I compile the participants’ emotional profiles based on their use of emotion words and their descriptions of emotional experiences during their spontaneous talk and in response to specific questions about how they felt at the time of a particular event (to which I will refer to as “feeling questions”). (In the construction of the participants’ emotional profiles, I was guided by several existing lexicons and lists of emotion words commonly used in literature on emotions [Clore, Ortony, & Foss, 1987; Shaver, Schwartz, Kirson, & O’Connor, 1987; Watson, Clark, & Tellegen, 1988]). Although emotion experiences—often referred to as feelings—are only one aspect of emotion, I use the terms emotion and emotional experience interchangeably to mean emotions of which the participants were “explicitly aware of as emotions,” which Lambie calls “reflective emotions” (p. 274). However, I also make a note about some—but not all—references to nonreflective emotional experiences, particularly in cases when they imply a new emotional experience, or when they add to the understanding of a previously mentioned reflective emotion.
Howard. Howard used 16 different emotion words\textsuperscript{31} to describe his emotional experiences such as aggravation, being loved, dislike, enjoyment, feeling good, getting mad, happiness, liking, love, loyalty, nervousness, sadness, unhappiness, and wonder (see Appendix E for a full list of emotion words). When using emotion words spontaneously, he most often mentioned enjoyment, followed by liking and love. For example, he used *I enjoy* in reference to “my family . . . meeting my cousins,” “making pictures,” “my job,” and “life.” He also said that he *enjoyed* going to college, some courses, and learning about police safety. He used *I like* to refer to his family, Canada, the computer, going to sport and autism groups, and living on his own. He used *I love* in reference to his four hobbies: “I love photography,” “I love to travel,” “I love my sports,” and “I love lapel pins.” As already mentioned, Howard also felt that “everybody loves [him]” and that his teachers and principals in one particular school also loved him. He also spontaneously expressed his dislike (“I don’t like to remember bad things”), disinterest (“I don’t have any friends from high school, anything like that, so, it’s nothing that I got interested in”), as well as wondering, which he mentioned while answering the question how he felt the first day of work but not in direct response to that question. Here is our dialog:

\begin{quote}
H: *I was nervous* [emphasis added],\textsuperscript{32} but I’m always nervous, so . . .
L: Are you nervous now?
H: No.
L: Then you’re not always nervous [jokingly].
H: *I was nervous* [emphasis added] last week [inaudible].
L: Last week when I interviewed you?
H: No, before I met you. *I wondered* [emphasis added] what you were going to ask me.
\end{quote}

Howard used most emotion words in response to my questions about how he felt at the time of the event he was describing, as was the case with the word *nervous* in the above quote. Thus, he used the word *happy* in response to a question about how he felt when he made his first photograph and *good* in reference to hearing that he was autistic. Because he did not like to talk about “bad things,” he provided only very limited information about his negative life experiences. However, he did indicate the nature of three such experiences and answered feeling

\textsuperscript{31} Following Ortony, Clore, and Foss (1987), I make the distinction between a reference to an emotion (“I was sad”) and implication of an emotion (I cried). Only emotion terms directly referring to emotions were counted as emotion words.

\textsuperscript{32} For ease of reference, in this section, I italicized participants’ emotion words.
questions about them. He said that he felt unhappy and very sad when a relative died, and, when talking about the difficulties associated with autism, he said, “I do get mad.” When asked to say more, he could not remember any details but said, “I probably get aggravated.” (It is interesting to note that he then added, “I’ll get back to you on that one. In two . . . in a few weeks, I’ll think of something.” Although I reassured him that it is okay if he does not remember, he reiterated, “I have to get back to you. I defer that question till the next couple of weeks [jokingly].” However, next time—which was, however, only one week after—when I reminded him about the question, he said he did not think of anything.) He did not provide any emotion words in reference to the third experience, bullying.

Sarah. Sarah’s used 20 different emotion words or expressions to refer to her experiences of abandonment, anger, boredom, enjoyment, happiness, hope, hurt, getting impatient, interest, liking, nervousness, pride, rejection, sadness, safety, and security, among others. She used most of the emotion words in response to the feeling questions. Of the 7 words she used spontaneously (angry, bored, enjoy, happy, nervous, interest, and upset), she used enjoy, happy, and angry most often. About getting angry, she said, “I would try to explain it to [customers], usually in a calming way. I would get the vibe from them that they are angry, and they end up making me angry.” She also said, “When I see them yelling, I tend . . . I could feel the anger between . . . the anger in them, and it goes right into me.” When describing one of her most significant life experiences, “getting left behind at school,” she spontaneously used two emotion words—nervous and upset:

Well, I remember my class and I going on a field trip to the local community center for skating, and I was getting my homework from my special education teacher, so I was about . . . I was in grade 4, so that was part of that program that I was in. And I remember myself and couple of my other classmates being ahead of me because we usually have to get our homework book signed by the teacher, and she was taking a long time, and I was getting nervous [emphasis added] knowing that my other regular class was getting ready to leave for the skating. So by time my teacher signed my book, I remember going back to the classroom—they were gone. So I was left behind. [...] I remember going . . . going back to my special education teacher, and I told her, “My class left without me,” and then, luckily, my friends’ class was still there, and they were going to the same place. So I ended up going on the bus with them, and then I was . . . when I got there, I didn’t feel like going in cause I was still upset [emphasis added].
It is also important to note that although Sarah did not elaborate on any of the emotion words she used in response to the feeling questions, she did make one remark about her emotional experience of sadness after her aunt died. She said, “Even to this day I still miss her.” This remark was also complemented with sadness in her voice.

Although Sarah did not use any emotion words expressing sympathy, concern, or interest in others’ wellbeing, these feelings were implied in several of her mentioning of being a kind person. She defined her kindness as being “thoughtful of other people,” by which she meant, “I would try to think of their feelings, their needs.” Moreover, her wishes for peace in the world and for “everyone to have their own home in the world” and “to have food too” are consistent with having these other-oriented feelings, to which I will refer as ethical feelings.

**Alan.** Alan’s emotional profile consists of 33 distinct emotional states, which, among others include anger, arousal, disgust, dislike, embarrassment, enjoyment, fear, feeling drained, feeling good, feeling sexy, fluster, guilt, happiness, hate, hope, inspiration, interest, liking, not fitting in, sadness, surprise, being upset, and worry. He used the words *enjoy* and *angry* the most. For example, he used the word *enjoy* in relation to one particular holiday experience, skating, talking to several people, and “I enjoy spending time watching hockey games or movies.” He used the word anger in reference to several incidents in which he lost control, one of which was already described. It is also important to note that Alan used the word *hate* in reference to his sensory sensitivities, and not to refer to people. He said, “I hated the smell [in the cafeteria], and I couldn’t stand the noise.” Here are two further examples of his uses of emotion words, one spontaneous, one solicited. When describing his obsessions, he made a spontaneous reference to the feeling of guilt:

> I also have an obsession with details, and everything must be this way or something bad will happen, or I’ll feel guilty [emphasis added], or, you know, god will strike me down, you know, things like that—there has to be a specific way, you know.

When responding to the question about his feelings after a behavioural outburst, he said,

> I just feel all flustered and drained [emphasis added] and I thought . . . it’s like, “What the hell just happened?” you know. I don’t know what happened, what got over me. It’s like drinking and driving. It’s like you don’t know what you . . . your mind is there, but you can’t stop what you’re doing. It’s like you’re a different person, it’s like that.
(Alan’s description of not knowing “what happened” is a good example of an implicit emotion. Although he did not use the word typically associated with the emotional experience he described—confusion—his description is fully consistent with it. In other words, his description is just a more personal way of saying “I was confused.”)

Alan’s emotion lexicon also included several mixed feelings, that is, complex feelings of different valence, such as bittersweet and guilty pleasure, which he mentioned in reference to his “obsession about magazines.” He said, “They [magazines] give me . . . make me feel sexy [emphasis added] and make me feel turned on [emphasis added]. It’s like [. . .] an alternative to having a girlfriend or making love, you know. Sometimes, yeah, it’s like guilty pleasure [emphasis added].”

Alan also mentioned two instances when he cried: one in reference to the death of a relative and the other in reference to his car accident. It is also important to note that although Alan did not use any explicit emotion words to refer to his concern for others, he made one remark which could be taken to imply such concern. As already mentioned, he said that he would like to “try to make life better for others, make someone happy, make life better for not just for you or for person who you want to be with, but for other people around you.”

**Mike.** Mike’s emotional profile contains references to 36 distinct emotional experiences, which range from feeling bad and feeling better to love, joy, and elation. They also include feelings of being heartbroken, embarrassment, worry, fear, and nonacceptance. Most of the emotion words Mike used spontaneously. As already discussed, Mike most often talked about his feeling of not fitting in and not being accepted. I briefly review some of the other emotional experiences he referred to or described.

As already mentioned, Mike also often talked about hope. For example, while talking about his chances for establishing “lasting friendship and love,” he said, “I always had hope” [emphasis added]. Likewise, when talking about how bullying ruined his confidence, and how he was slowly restoring it, he said, “I build confidence based on hope. I work a lot on hope.” But perhaps the best example of Mike’s hope (its depth and power) could be found in the already-
quoted example of him thinking about his future and the possibilities of having to “retire medically” from his job and his marriage not working out: He said that even if these events do happen, he hopes to accept them as inevitable and to continue living his life the best he can.

Mike often used words related to fear. For example, talking about being a hard worker and a serious person, he said, “If I’m not serious, or I don’t put my nose to the grindstone, I’m scared [emphasis added] that I’m gonna fail—because I have.” Describing his visit to the hospital where he was examined by a psychiatrist when he was six-year old, he said,

I went for testing and it was very scary [emphasis added] because, I was only a little tiny guy—I was very small, like my youngest son—very, very small little kid. And I remember going there, and it was all smoky . . . the rooms . . . and the guy had a big cigar and all that . . . And he had a book—it had all these . . . colored . . . almost look like an eye test.

Mike’s worst fears were related to bullying. While talking about the difficult time he had adjusting to the new school in which he was bullied by both students and teachers, he said,

It was a very frightful [emphasis added] world. It still is in a lot of ways, by the way. It was a very scary [emphasis added] world. It was very dark. It was very dark, and it was black, and actually I am being honest, I see a lot of sunshine, but when I was growing up, like, I remember Grade 7 and eight being very very dark, very emotionless [emphasis added], like, I cared, but I couldn’t help that I couldn’t get a grip on anything. That’s basically it. I don’t know if it makes sense.

According to Mike’s explanation in the follow-up interview, the words darkness, blackness, and emotionlessness refer to what he would now call “depression,” but at the time, he “felt blackness.” And he reiterated, “But it was all dark. There was nothing to look forward to.” Although “feeling blackness” does not appear in any of the emotion lexicons that I consulted, it is clear that the expression refers to a felt experience of extreme sadness on which Mike was able to reflect (i.e., it was a reflective emotion).

Mike’s emotional lexicon also includes so-called self-conscious and social emotions, such as pride and embarrassment. For example, in an already-quoted interview segment related to his experiences of being bullied, Mike said, “I used to be embarrassed [emphasis added] all the time.” In another previously-quoted description of his experiences with being bullied, Mike also
expressed several other feelings related to being humiliated, such as feeling bad, worthless, and like trash. He also mentioned a feeling of pride—in the context of a potential retirement due to “medical” reasons, which, he said, would hurt his pride.

When talking about joy, Mike distinguished between several intensities: enjoyment, excitement, elation, and joy that cannot be expressed in words. For example, talking about meeting with people who have similar interests, as opposed to communicating with them over the Internet, he said, “Once in a while you meet with real people, and I enjoyed [emphasis added] that.” Likewise, while talking about his hobby, he said, “I enjoy [emphasis added] to talk about all kinds of [paranormal] phenomena.” Talking about his job, he stated, “I enjoy [emphasis added] having the responsibility.” However, asked how he felt when his children were born, he said, “Oh, elated. Excited. [emphasis added] I don’t even . . . I don’t have words for it.”

Mike also reflected on different kinds of love, such as a passionate and “deeper” or “true love.” When describing his first adolescent love, he said, “It was like fire and . . . It was unreal—the passion [emphasis added] was unreal.” Talking about a conversation they once had, he said: “I said [to her], ‘I need you to know that I love you very much, and I always have and always will.’” On the other hand, when talking about his wife, Mike had a different kind of love in mind. He said, “I love [emphasis added] her very much [softly]. I know she loves [emphasis added] me—I know she does—I can feel it. Okay. It’s my own way, but . . . but I know she loves [emphasis added] me—I do.” He then explained: “People say, ‘Oh, I fell in love with that person.’ No, that may be . . . [clears throat] that could be love, but there is a deeper love [emphasis added] that develops for somebody when you actually work [lifts his hand from the table and drops it back making a sound] with them.” Based on his experiences, he then argued against the popular view that autistic people cannot love:

They can love [emphasis added] too. And that’s BS for people that say “Aspies [jargon for people with Asperger syndrome] cannot love [emphasis added] people”—that’s not true—they can. But it takes them a long time, [lifts his hand from the table and drops it back making a sound] to build . . . I build [lightly banging the table several times with his hand] what I have [the same movement and sound] based on my past, you know, the memories of holidays [lifts his hand from the table and drops it back making a sound] and pictures of, you know, [the same movement and sound] of going places and talking and doing stuff together and working [the same movement and sound] as a team and all that
kinda stuff—that’s where [the same movement and sound] I think true love [emphasis added] comes from.

Although Mike used the word happy several times during the interview, he never used it in reference to something he already felt and always in reference to a desired experience. For example, he reported saying to his wife (when she told him that he can “pursue other women), “I wanna be happy [emphasis added] with you.” Likewise, when asked how life would be if he were not autistic, he said, “I’d have a lot more friends. I’d have a lot of experiences. I would have, you know, met a lot more people and probably had a greater, wider experiences and [pause] even been happier [emphasis added].”

Mike also mentioned a variety of other feelings including feelings of relief and feeling better (in an already-quoted reference to getting the Asperger syndrome diagnosis), wonder, feeling confused, as well as feelings of worry and of security. For example, while describing his obsession with security, he said, “I was so worried [emphasis added] about the house— somebody can break into the house.” When talking about joining the army, he stated, “I felt security from it because it’s how I ever knew around me” (because his father was also in the army). It is also interesting to note that, in contrast to some other participants (Pierre, Alan, and Sarah) who mentioned anger the most often, Mike did not mention it once.

Finally, Mike mentioned several feelings that do not appear in standard emotion lexicons.33 For example, talking about being in the army, he said, “I feel trapped.” He also remarked on his intuitive feelings about “people who say that they’re good, and I don’t think they are, like [. . .] I get feelings sometimes about stuff, and . . . I don’t know . . . I perceive the world a bit differently, I believe.”

Orville. Orville used 41 emotion words to refer to his feelings, both spontaneously and in reply to feeling questions. Some of the emotional experiences that make up his emotional profile include autistic feelings, being puzzled, boredom, concern, confusion, depression, devastation, dismay, envy, esthetic feelings, fear, hope, isolation, marvel, sadness, shock, and surprise. As

33 It should be noted that these feelings were not counted as emotion words although they clearly convey descriptions of emotional experiences.
previously reviewed, Orville most often mentioned feelings of social isolation and not belonging. For example, he said, “[I] felt, even in group hikes, and that, isolated from the others”; “I feel still isolated,” “I feel totally isolated.” Here is a longer description of this feeling:

[I’ve] been involved with so many groups over the years, but it’s still the means of bonding in such groups, even, like, that hiking trail club . . . after setting it up and being involved with it for over 10 years, I still felt, even in group hikes, and that, isolated from the others. We’d been going down the trail together, the others would be talking about, “Oh, look at that bird over there, isn’t that such and such warbler?” and stuff like that. But I may accept whatever they say was that, but when the hike was over, I’d go home, and I’d, again, feel totally isolated [emphasis added] until maybe the next hike another month away. And no bonding was ever made with anybody.

In the following excerpt Orville described the feeling of not belonging or “not getting the bonding” (giving it a special label associated with meetings: “boardroom feeling”):

But still the bonding doesn’t seem to be there. Again, it seems to be that boardroom feeling—the same feeling I get when I attend the [Ottawa] writers’ circle. I go there, people chitchat around the room, they might stop . . . well, one person reads a small story, another person reads a poem, and on and on, and others discuss it, but I still feel as though I am not getting the bonding I am looking for with anybody there. And after a number of meetings at such groups there, my interest starts to wane, and it starts to go downhill, when I don’t feel like attending anymore.

Many years of accumulated experiences similar to those he just describe led Orville to develop a special kind of feelings, which he called “autistic feelings” and described as feelings of living “in a world of [his] own”—a “bubble” that prevents him from “connecting to others.”

Orville also described in some detail his special feelings for nature and abandoned railways. He called the former “esthetic feelings toward nature” and “feeling a common connection with nature,” which he described as follows:

Not just nature in a sense of animals and trees and grasses, but nature in this global sense—almost beyond the Earth and that—sense of being part of the universe. And just as much as I feel I’m important, I feel that every leaf of every tree and every blade of grass and every droplet of water in the stream and on and on in the world is very important.

Orville described his two feelings toward abandoned railways—interest and marvel:
All my life I’ve been interested in trains, especially railway tracks for some reason. It wasn’t the train itself but the track itself . . . how I could go down the track, and how I could look right into the horizon and marvel at how these were laid with such precision over a hundred years ago.

Accordingly, Orville felt dismayed at the recent “abandonment of all these railways all over Ontario.” He also reported about another set of complementary feelings in regard to getting the diagnosis of autism. As already reviewed, he said that he felt relief when he got diagnosed and that if he never got the diagnosis, he would feel more and more frustrated not knowing why he had difficulties bonding with others.

Orville also made several references to fear, using words such as fearing, terrifying, and afraid. For example, he said that having to do small talk without understanding its meaning, “feels terrifying to me.” He also said, “I was almost afraid to approach people in a lot of ways fearing that they had a power over me that I couldn’t have over them.”

Orville also mentioned several other positive emotional experiences. Talking about camping with his scout group, he said, “Signing around the camp fire sure made me feel very good,” and about one of his achievements, the preparation of the village map when he was 18, he said that it was an “emotional surprise” that many people wanted to help him with that project and added that he “felt speechless” and “almost like somebody from higher . . . some other ether was looking down after me at the time, is what it felt like.” He also said that the successful production of the map made him feel more self-confident.

As in the just-mentioned example of feeling as if somebody was “looking down after [him],” in his effort to describe his feelings, Orville used several other similes. For example, describing a school incident, he said, “[It] gave me almost dizzy spells is what it made me feel like.” As already quoted, with regard to others giving him advice about persisting in trying to establish relationships, he said “almost like pouring alcohol down my throat, is what it felt like every time somebody came up with that.” In another, also already-quoted remark with reference to his suspension from college, he said “[it] felt, [to] use layman’s term, like the carpet had been pulled off from under my feet.” Describing his frustration with his inability to “get the message
[across]” to a person, he said that he felt like “talking to a brick wall,” “like banging my head against the brick wall and wondering if the brick wall will ever tumble”

Orville also described several other emotional experiences that do not fit any known emotion words. For example, as previously quoted, he said that he “feels” to “have a different culture than a lot of people” and that the idea of autism somehow having to be “fixed” “feel[s] foreign to [him].” He also described his feelings related to difficulties communicating with others:

Sometimes I feel that when I am communicating with other people that the only way I can get my message through is to raise my voice. And even one time during video interview with this doctor [. . .] I did [raise] my voice and was even putting my hand down on the table [taps], and she even asked me, “Why do you do that?” I said, “Because I feel it’s necessary [emphasis added] for emphasis,” I said, “to try and get the message through.” Though a lot of times when I say things [in] just everyday language, like I’m speaking now, people seem to half-hear what I say, and it seems to just disappear from them the next minute as though I haven’t even said anything to them, just like saying . . . they ask me, “How’s the weather been around where you are?” and I say, “Oh, it’s been pretty well,” and then they change the subject right away as though what I said really didn’t seem to even register with them. And I think, “Why even communicate with other people if it’s just go in one ear out the other, [it’s] what it feels [emphasis added] like.

Finally, it is important to note that Orville did not mention anger, even once. And although, as just described, he did imply feeling frustrated, and even used the word in reference to not knowing about the sources of his social difficulties, he never used it in reference to any particular event or person.

**Jimmy.** Jimmy’s emotional lexicon consists of 43 emotion words, which include, among others, aloneness, anger, anxiety, comfort, confidence, concern (both for self and others), depression, desire, discomfort, empathy, enjoyment, fear, happiness, hate, hope, insecurity, isolation, jealousy, love, relief, and surprise. He used most of the emotion words spontaneously, mentioning words referring to anxiety and fear most often, followed by love. For example, he stated,

I feel anxiety [emphasis added] about everything. I feel afraid [emphasis added] of everything. I’m afraid [emphasis added] to [sighs] just go walk into the store . . . going to the store causes me anxiety [emphasis added], leaving the house, sometimes. Any . . . any situation, anything new scares me—I hate [emphasis added] that.
In addition to the word *afraid*, which he used in reference to strangers, crowds, and noisy places in particular (as previously quoted), Jimmy also used the word *terrified* to refer to his feelings prior to going to an art camp when he was 14, about which he said, “It caused me a lot of anxiety. I was terrified. I did not wanna go.” His several references to love were made in connection with the arts and nature, such as in “I’ve always loved music,” “I’ve just always loved art and music,” “I like to take pictures. I’ve been doing that for about a year, and I love it,” and “I love nature and being out there.”

Jimmy also mentioned feelings of satisfaction, attraction, interest, and liking in reference to arts. For example, he said, “I get a lot of *satisfaction* from creating something” and “Anytime I was recognized for, like, my artistic ability and things like that, I always *like* that.” He also said, I’m *attracted* [emphasis added] to patterns and things like that. I used to draw a lot as a kid. I kinda got away from it as I got older. Even in high school, I started kind of losing *interest* [emphasis added] in it. I still *like* [emphasis added] to, sort of, doodle, but beyond that, I never really got into pursuing painting or drawing, any further than that. But photography, I really *like* [emphasis added] editing, I *like* [emphasis added] taking things that other people have done and, sort of, changing it, making it better.

However, Jimmy’s strongest feelings of *happiness* were associated with socializing. He described his happiest experience as follows:

I do remember one time, one party, one birthday party that was at a bar when I was 21. [. . .] Everyone there was there for me and I was *happy* [emphasis added] about that because my younger sister came, and she was with couple of friends, and she was impressed because the place was packed. They were all friends of mine. They were all there for me, and they were giving me gifts, you know, playing a show and taking me up on stage and stuff like that. [. . .] I was *comfortable* [emphasis added] and *happy* [emphasis added] and *confident* [emphasis added] because as much as I didn’t like attention or spotlight or things, it was good then, because it just felt good [emphasis added], it felt different because it was all for me, and I knew everyone there, that kinda thing.

This quote also gives credence to Jimmy’s statements about his positive social feelings such as “I *enjoy* the company of other people,” “As I’ve grown older, I do have more *desire* to be around people,” and “I *miss* being friends with him.” He also expressed his social feelings when
describing his third unsuccessful attempt at finishing college, when he mentioned his feelings of *aloneness, isolation, and hate of being*—and feeling—alone:

The reason I didn’t finish is mainly social. I just really had a hard time out here in school and with the people. I didn’t have a car, and I had blocks of time in the middle of the day for three or four hours, where I had no classes, and I couldn’t really leave campus because I didn’t have a car, so I would just kind of wonder around. I didn’t have any friends. I couldn’t make friends. Most of the people in class were a few years younger than me, and I just found it really difficult to make friends for some reason that year, and I *felt really isolated and alone* [emphasis added], and I would just kinda wonder around. I just *hated* [emphasis added] it.

Jimmy’s lack of success in establishing and maintaining relationships led him to start *feeling unable* to do so. He said, “I just *feel very anxious* [emphasis added] about it, and I *don’t feel like I have the ability* [emphasis added] to do it.” These and other negative social feelings mentioned above contributed to Jimmy’s “*feeling like you are not part of the world* [emphasis added], you are watching it on TV; more like you’re an observer, you’re not really in it.”

Jimmy’s references in the above long quote of *hating feeling isolated and alone* and his other reference to *hating being afraid*, are particularly interesting because they represent instances of *meta-emotions*, or emotions about emotions (Gottman, Katz, & Hooven, 1997). (It is important to note that one other of Jimmy’s references hate was in connection to his restaurant job and that none were in reference to people.)

In addition to using a variety of emotion words and emotion expressions, Jimmy also described several of his behaviors associated with his more intense emotional experiences. For example, he described several instances of screaming, crying, and hiding from others when he felt afraid of people in crowded and noise spaces. He also cried when he diagnosed himself as autistic and when he felt sorry for victims of bullying, which he described as follows:

I was always really sensitive to bullying, and I use to feel really *empathetic* [emphasis added] towards other kids that were . . . when I saw it, it used to really *upset* [emphasis added] me. I remember laying in bed crying at night when I was a kid because of watching some kid get beat up.
In addition to Jimmy’s explicit use of the word *emphatic* in the above quote and the description of behavior that supports its use, as already mentioned, Jimmy also expressed his concern for others several times during the interview, most notably in his description of himself as an understanding person, when he said that “I’ve always wanted to make people around me happy. I’ve always been concerned [emphasis added] about how people around me feel.”

Although Jimmy did not use the word *apathy*, his two descriptions of his lack of interest and enthusiasm are fully consistent with it. On one occasion, he said, “I’m quite *comfortable to just sit in the chair and not do anything.* I have to really, kind of, force myself to do things. I’m trying to do that more now.” On another occasion, he remarked, “I just, you know, I’m *always content to just kinda sit, so at odd time, for whatever reason, I’ll feel like maybe getting up and doing something.*”

Finally, it is interesting that Jimmy was not satisfied with his ability to express his emotions and said, “I feel out of touch with my emotions. I feel like I don’t know how to express my emotions; I never laugh.” When challenged on the last point—on the basis of observed instances of laughter—he said,

> I mean, I do, but it’s not like a real laugh, like verbal kind of a laugh, it’s more like an internal sort of thing. [. . .] I can’t laugh hard. If I get to the point of I’m laughing hard, it’s more of a cry. I don’t make any sound.

**Geoff.** Geoff’s emotional profile contains references to 72 distinct emotional states, which include alienation, attraction, bewilderment, depression, devastation, envy, esthetic feelings, excitement, fear, feeling I’m-no-good, fright, frustration, gratefulness, hope, love, pride, rupture, sadness, spiritual feelings, suffering, and terror, among others. I present only a small sample of Geoff’s descriptions of his emotional experiences, focusing on those he mentioned more often, or which were not mentioned, or were mentioned less often, by other participants. For example, he said that he *loves* music and subway maps, that he is *proud* of his creativity and that he has *esthetic feelings* towards “well designed subway map[s]”:

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34 Apathy literally means “without feeling”; more descriptively, “lack of interest, enthusiasm, or concern” (ODE, 2005).
35 Geoff wore a t-shirt with a Chicago subway map on it when he came for the second interview.
I think because it’s a different way of seeing the world, there are certain things I might see beauty in that the average person would not. You know, like, for instance a really well designed subway map. I would look at that, and I would see this beautiful . . . and get great pleasure from looking at it.

Geoff also described many feelings related to his spiritual experiences. For example, he described his feelings associated with his spiritual awakening when he went to the cemetery to pay tribute to his dead cousin, as follows:

It was quite intense, and I was drained afterwards. I was really drained. [. . .] I was quite, you know, I was tearing up, you know. [. . .] Very emotional, yeah, and I was . . . I was really just trying to, you know, keep myself together and do what I was there to do without, you know, falling apart, crying and crying, you know, so it was hard. [. . .] I didn’t break down, but I was on the verge of.

Describing his feelings associated with his decision “to put [his] life in [his dead cousin’s] hands,” he said,

I feel a bit of a sense of burden being lifted in the sense that I no longer feel that I’m totally responsible for all that happens, that it’s not something that I have to worry about that, or I have to do something about, or I have to act. Sometimes I just have to experience things and just accept them and say, Okay, that’s what’s happening now. You know, and if it’s a trying time, I might, you know, pray for strength to get through it, or pray to be guided toward a certain action, something like that, but I no longer feel that I have to fix everything. And that’s a tremendous relief.

Geoff had other feelings associated with his spirituality: “I also feel grateful that I was guided to a place where this decision would present itself because it’s not something that it really would have occurred to me otherwise.” Thinking back about his first experience of hearing music on the radio, he found some similarities with his spiritual experiences:

I consider it almost like my first spiritual experience even though there is no . . . it’s not really by name but just listening to the radio, listening to all these songs, singing along, and, I guess, because of the way my brain is wired—I’m very verbal and auditory, you know—I would hear a song, and I would be able to listen to the whole song, but would also be able to pick out, Oh look, this tambourine’s coming in right here over in the . . . you know, right in my headphones, right there, you know: I’d hear the tambourine coming and go, Whoa, look at that. And I was just so excited.
Among other feelings Geoff referred to often were those associated with his experiences of rejection by a girl when he was an adolescent. As previously quoted, he felt “devastated” at the time, cried at first, and then went into “an emotional shut down that lasted all through high school.” He also said, “I came out of it feeling I’m no good [emphasis added], I’m no good.” Describing himself in his youth, he said, “I was logical, very [pause], I don’t know, scholarly almost, I wasn’t in touch with my feelings at all. I didn’t really want to be.” He also said that he “got in touch” with his feelings when he fell in love for the first time:

I was really, actually, out of touch with my feelings from [. . .] about 13 to 17, especially. And I guess what got me in touch with my feelings again is [. . .] there was a girl in the neighborhood I lived in who developed a crush on me. And she was younger. And this was the first time anybody showed me anything, has showed me anything at all. Up to this point, I had some pretty bad experiences. So I, basically, I guess . . . the short version is I fell in love [emphasis added]. And I couldn’t stop it, you know. I couldn’t stop the feelings, and there they were, which is wonderful, I think now, but it was, kind of, strange at the time.

As already quoted, Geoff also described his feelings of alienation. He said, “I do feel a bit like an alien [emphasis added] in this world, and I don’t, in general, find it very welcoming.” He reiterated the importance of this feeling by mentioning it several times. For example, on another occasion, he said, “I definitely feel like an outsider [emphasis added]” as well as “I feel very different from everyone around me” [emphasis added].

Among several implicit feelings found in Geoff’s account, I highlight two. First, a feeling of determination, which was implied in his remark “I do feel driven to complete tasks,” and second, a feeling of progress: “I feel like I’m getting somewhere” and “I feel like I’m getting to where I want to be.”

Finally, it is also important to note that Geoff never mentioned anger. The closest word to anger that he used was frustration. However, this was not in relation to any particular event but rather with his general lack of success with dating

9.3.5.3.1.2 Interpretative Summary
My focus on the participants’ emotional profiles is twofold. On the one hand, awareness of emotions is an important aspect of self-understanding (Lambie, 2009). Emotions, among other things, represent personal interpretations of events—broadly defined as anything that elicits an emotion. However, these interpretations are not always conscious. When they are, we are able to label them (by using an emotion word), describe them (to self and others), understand them, and, if desired, change them (Frijda, 2009). On the other hand, the use of emotion words tells more about people than just how much they understand their emotions. Indeed, Magai and Haviland-Jones (2002) argued that emotion words tell us a lot about what kind of persons their users are. According to these authors, emotion words are fractals (i.e., smaller version of the whole thing, p. 392) of personality: “emotional words, their frequency, their explicitness, their intensity, all tell a story about the speaker or the writer” (p. 229). Magai and Haviland-Jones further suggest that a central emotion word is an “emotional signature” (p. 230) of a person. I accept this view and start with a review of the participants’ emotional signatures. However, in addition to the central emotion word, I also consider other emotion words that are used more frequently and/or with a particular force or conviction.

_**Emotional profiles as fractals of personality.**_ This study’s participants painted an array of emotional profiles that range from almost black-and-white (e.g., Howard) to very colorful ones (e.g., Geoff). Although many participants had the same emotion word at the core of their profiles (e.g., anger in case of Pierre, Allan and Sarah, and depression in case of Mike and Geoff), no two participants had the same combination of emotion words that make up their whole life-spaces. Thus, Pierre’s emotional profile is made up of anger, enjoyment, and love; Alan’s of anger, enjoyment, and feeling of not fitting in; Sarah’s of anger, enjoyment, and happiness; Howard’s of enjoyment, liking, and love; Jimmy’s of fear, anxiety, depression, and love; Mike’s of...
depression, fear, feeling of not fitting in, and hope; Geoff’s of depression, fear, spiritual feelings, love, and alienation; and Orville’s of isolation, autistic, esthetic, and spiritual feelings.

It is also interesting that although anger was central to 3 participants (Pierre, Sarah, and Alan)—and Jimmy referred to it once (cf. to 14 uses by Pierre)—it played no role in the accounts of half of the participants (Mike, Orville, Geoff, and Howard). Likewise, although fear was an important emotion in 3 participants’ accounts (e.g., Mike, Geoff, and Jimmy’s) and was mentioned at least once by Orville and Alan, 3 participants (Pierre, Sarah, Howard) never used any of the emotion words to refer to it. It is also worth noting that whereas alienation was an important component in Orville and Geoff’s profiles, and the related theme of not fitting in had an important role in accounts of 3 other participants (Mike, Alan, and Sarah), none of them were found in Pierre or Howard’s accounts.

**Emotional understanding.** In addition to telling important stories about the participants, this study’s participants’ emotional profiles also tell an important story about autism. The participants used a wide assortment of emotion words (i.e., in excess of one hundred), phrases, and descriptions. Most of the emotion words and expressions the participants reported were commonly accepted; however, they also reported a number of personal descriptions of their emotional experiences as well as several unique expressions.

For the most part, the analysis of the participants’ emotional understanding includes what Lambie and Marcel (2002) refer to as “categorical-emotion experience,” that is, instances of reporting the content of experience as an emotion category such as “sadness” (as in “I was sad”) and only “self-focused” experiences (that is, experiences that include an explicit reference to self, such as in “I was sad” as opposed to “world-focused experiences,” such as in “The world was black”). This choice was made because the current conceptions of emotional understanding in autism are based on the narrow conceptualization of emotional experiences as categorical and self-focused. However, to illustrate the variety and complexity of the participants’ emotional experiences, some of the participants’ metaphorical and world-focused experiences were also noted.
In general, this study’s participants’ emotional profiles suggest not only that the emotional world of autistic individuals is more complex and varied than is usually assumed, but also that autistic individuals can identify their emotional experiences, and label and describe them—to themselves and others. Of course, as in the typical population (Magai & Haviland-Jones, 2002), there were large individual differences among participants in their verbal emotional expressions. However, only the account of 1 participant (Howard) could more easily fit into the stereotypical view of autistic individuals’ understanding of their emotions as his emotional experiences appeared rather undifferentiated and his emotional vocabulary was rather limited (at least compared to the accounts of the other participants: whereas the range of emotion words for all but one other participant was between 30 and 72, Howard used only 16 such words). That other participant was Sarah, who used 20 distinct emotion words. However, although she did not have a habit of using emotion words spontaneously, she answered all questions about her feelings using appropriate labels for the experiences she was describing and thus also displayed a greater understanding of her emotions than is usually associated with autistic individuals. It is also important to note that the participants’ working emotional lexicons (particularly those of Pierre and Alan) were much greater than their emotional profiles suggest. That is, they mentioned many more emotion words in their descriptions of others, which they often used as part of telling about themselves, such as in descriptions of book and movie characters.

In general, most participants did not appear to have any difficulty with emotion vocabulary, and they spontaneously, and generously, used a large assortment of emotion words and expressions. They also often described their thoughts and behaviors related to the emotion labels they used. As in the case of non-autistic individuals (Magai & Haviland-Jones, 2002), they also implied many more emotions in the descriptions of their experiences, suggesting that their emotional understanding is greater than simple label counting would suggest.

In addition to using emotion words to appropriately convey different kinds of emotional experiences, the participants also adequately used emotion words to convey subtle differences in the intensity of their experiences. For example, they differentiated between liking and love. Four participants used the word love to refer to the sources of their greatest enjoyment: music (3 participants; Pierre, Geoff, and Jimmy), photography (2; Howard and Jimmy), nature (2; Orville and Jimmy), arts (1; Jimmy), sports (1; Howard), travel (1; Howard), and objects (lapel pins; 1;
Howard). (It is important to note that the participants corroborated the difference in the intensity of this emotion by changes in nonverbal behavior such as tone of voice and facial expressions.) They also distinguished between different levels of *joy*: from simple enjoyment, as in “I enjoy walking,” to rapturous joy (Geoff) and elation (Mike); *sadness*: from simple sadness to devastation (Geoff), depression, and emotionlessness (Mike); and *fear*: from being afraid (Orville, Alan, Geoff, and Jimmy) and scary (Mike and Geoff), to being frightened (Mike and Geoff), terrified (Orville, Geoff, and Jimmy), and horrified (Geoff), among others.

One of the participants, Geoff, appeared to have a much greater understanding and facility with emotion words than the other participants. He mentioned 72 distinct emotional experiences in contrast to the 43 used by the participant with the second highest number of emotion words (Jimmy). Some of the factors that could have contributed to this difference could, perhaps, be found in his unique life history which includes studying psychology (at the undergraduate level), spending years in psychotherapy and self-help therapy groups, reading biographies (his favorite genre), and writing his own autobiography. He himself suggested that the latter activity greatly contributed to his better self and emotional understanding.

**Thematic analysis.** A thematic analysis of emotional profiles of this study’s participants reveals some important patterns. First, the only emotion word mentioned by all of the participants was *enjoyment* (mentioned in one of its syntactic forms, usually *enjoyed* and *enjoy*). All but one participant also mentioned *liking* (all but Orville), *dislike* (all but Sarah), *happiness* (all but Orville), *hope* (all but Howard), and *interest* (all but Howard). All but 2 participants (Sarah and Alan) also mentioned *love*. However, only 2 participants (Mike and Geoff) used the word *love* to refer to others, whereas 4 participants used it in reference to sources of enjoyment or special relationships with world phenomena, as reviewed above. Because this meaning of love appears to differ from liking only in its intensity, and because Orville, who was the only participant who did not use the word *like*, did use the word *love*, we can assume that all participants also referred to *liking/loving*. Indeed, although the participants did not use the word *passion* to refer to their strong emotional experiences associated with engaging in their interests, the intensity of their expressions—both verbal (e.g., the use of special words and phrases such as *love, always loved,*

38 One participant (Geoff) used the word love in reference to both others and a source of enjoyment, music.
biggest love in life, almost like my first spiritual experience, rapturous, unbelievable, exciting, very important, so important, fanatic, was really into, what I really wanna do, common connection, brings me some kind of good feeling and sort of don’t-think-about-anything-else) and nonverbal (e.g., the excitement and enthusiasm of their voice, intensity of speech, emphatic emphasis of words, level of detail, frequency of reference to the objects of their passions, facial expressions, and their general demeanor, all of which expressed extreme levels of enthusiasm and involvement)—are consistent with the word’s meaning. In fact, the word passion is the best summary word—from a third-person perspective—for their accounts of emotional experiences related to their interests and, at least for several participants, for their accounts of their entire lives.

When different expressions of anxiety are put together—anxiety, used by Jimmy; worry, used by Pierre, Mike, and Alan; nervousness, used by Sarah and Howard; and concern, used by Orville and Jimmy—then it could also be said that all participant mentioned anxiety. This is particularly important in light of autism literature which consistently reports high incidence of anxiety disorders among autistic individuals (Ghaziuddin & Zafar, 2008). Given the high incidence of depression among adult autistic individuals (Ghaziuddin & Zafar, 2008; Sterling et al., 2008), it is somewhat surprising that although 5 participants mentioned feeling depressed (Pierre, Mike, Orville, Geoff, and Jimmy) at some point in their lives, and 3 of these participants (Mike, Geoff, and Jimmy) also used the words that indicate apathy, which is one of the symptoms of clinical depression (APA, 1994)—Mike used the word emotionless, Geoff, emotional shutdown, and Jimmy said, “I’m quite comfortable to just sit in the chair and not do anything”—only 1 of these participants (Jimmy) reported currently having both depressive and apathy feelings. It is also worth noting that only 1 participant (Geoff) mentioned having suicidal feelings (in the past), which are also sometimes mentioned in the literature on autism (e.g., Green et al., 2000).

39 The word passion is used in a sense similar to that proposed by Hegel (1832/1956):

Human activity as resulting from private interests—special, or if you will, self-seeking designs—with this qualification, that the whole energy of will and character is devoted to their attainment; that other interests (which would in themselves constitute attractive aims), or rather all things else, are sacrificed to them. (p. 23)
All participants also referred to at least one of the *epistemic feelings* (feelings that refer to knowing; de Sousa, 2008), such as boredom, inspiration, interest, surprise, and wonder. Moreover, their many references to a *love* for creative thinking (Pierre, Orville, and Geoff), reading (Pierre and Jimmy), researching (Mike), as well as reviewing old calendars (Sarah) are also instances of epistemic feelings. The reference to feelings stemming from knowing is in accord with autistic individuals’ well-known passion for knowledge, which, as previously reviewed, is mentioned by many autistic individuals (e.g., Holliday Willey, 1999; Jansen, 2005; Schneider, 1999) as well as clinicians (e.g., Attwood, 2006; Gillberg, 2002).

Likewise, all participants made at least one either implicit or explicit reference to one of the *ethic feelings*[^40] such as care or concern for others, feelings of justice, and loyalty. The *care or concern for others* was explicitly mentioned by 4 participants (Pierre, Sarah, Alan, and Jimmy) and implied in the accounts of 2 other participants (Mike and Orville) whereas the feeling of justice was implied in all accounts except Howard’s. Two participants made references to loyalty (Pierre and Howard), and 1 participant (Jimmy) referred to *empathy*. The participants’ spontaneous references to (or implications of) ethic feelings are particularly important because such feelings are usually not associated with autism (e.g., Baron-Cohen, 2005; de Vignemont & Frith, 2007). Indeed autistic individuals’ presupposed inability to empathize is thought by some to be the “core deficit” of autism (e.g., Baron-Cohen, 2005; Brothers, 1989; Gillberg, 1992). Moreover, this view made Baron-Cohen deny autistic individuals a true other-focus and de Vignemont and Frith (2008) to question autistic individuals’ ability to have a sense of morality. However, as philosopher R. C. Solomon (1990) argued, many true (i.e., other-focused) moral feelings, feelings of justice in particular, stem from individuals’ experiences with and feelings of injustice. This study’s participants’ experiences with injustice—from their experiences of being bullied in particular—are consistent with Solomon’s proposal, and cast some doubt of the empathy as the only source of moral feelings—which is a proposal made by Hume (see a discussion in de Vignemont & Frith, 2007), but which was recently challenged (on other grounds) by Kennett (2002) and McGeer (2008).

[^40]: I use the term *ethic feelings* to refer to positive moral feelings towards others and thus distinguish them from a broader term *moral feelings*, which usually refers to feelings of contempt, anger, disgust, and the so-called “self-conscious” emotions such as shame, embarrassment, and guilt, as well as compassion, empathy, gratitude, and elevation (Haidt, 2003), but which rarely includes feelings such as care, concern, feeling of justice, and loyalty.
All except 1 participant (Mike) also used either emotion words for, or implied, *esthetic feelings*. In most cases, these feelings were related to the arts and nature: *music* (5 participants; Pierre, Geoff, Jimmy, Sarah, and Alan), *photography* (3; Orville, Jimmy, and Howard), *nature* (2; Orville and Jimmy), the *arts* (2; Jimmy and Pierre), *film* (2; Alan and Pierre), *subway maps* (Geoff), and *old railway tracks* (Orville). These feelings are consistent with the above discussion on the participants’ strong emotional reactions to their interests. It is quite possible that it is these feelings towards the objects of their special interests that contributed to the special status of these interests in the participants’ lives. These feelings are also consistent with Asperger’s (1944/1991) original observations that some autistic children possess a “mature degree of art appreciation” (p. 73), as well as with autobiographical accounts (e.g., McKean, 1994; Purkis, 2006; Schneider, 1999; D. Williams, 1992; see also Sacks, 1995).

One kind of feelings—*spiritual feelings*—mentioned by 2 participants (Orville and Geoff) are worth highlighting because they are rarely, if ever, mentioned not only in the autism literature but in psychological literature in general. Orville described his spiritual feelings towards the nature whereas Geoff had such experiences in his encounters with music and his “guardian angel.” Orville’s description of his spiritual feelings towards the nature seems to include a mixture of very intense and deep feelings such as awe, esthetic feelings, and feelings of connection, oneness, and belonging. As such, they bear a close similarity to what Maslow (1964/1970) termed “peak experiences,” which, among other features include the feelings that the world is good and beautiful and that one is a part of it—that one belongs in it. It also involves an extreme level of concentration and a tendency to see things as being equally important (a tendency not to evaluate, compare or judge), all of which Orville described. It is interesting that Maslow found that not everybody has these experiences, which is, perhaps, one of the reasons why such feelings do not appear in any of the major emotion lexicons (e.g., Clore et al., 1987; Fehr & Russell, 1984; Johnson-Laird & Oatley, 1989; Rozin & Cohen, 2003; Watson et al., 1988), which are, for the most part, based on the most commonly experienced emotions. However, the rarity of an experience does not invalidate its authenticity, as is apparent from the following quote of the philosopher Emerson (1836/1999), whose spiritual experience is quite similar to that of Orville, as well as to those of Maslow’s “peakers.” Emerson wrote,
In the woods, we return to reason and faith. There I feel that nothing can befall me in life,—no disgrace, no calamity, (leaving me my eyes,) which nature cannot repair. Standing on the bare ground,—my head bathed by the blithe air, and uplifted into infinite space,—all mean egotism vanishes. I become a transparent eye-ball; I am nothing; I see all; the currents of the Universal Being circulate through me; I am part or particle of God. The name of the nearest friend sounds then foreign and accidental: to be brothers, to be acquaintances,—master or servant, is then a trifle and a disturbance. I am the lover of uncontained and immortal beauty. In the wilderness, I find something more dear and connate than in streets or villages. In the tranquil landscape, and especially in the distant line of the horizon, man beholds somewhat as beautiful as his own nature.

The greatest delight which the fields and woods minister, is the suggestion of an occult relation between man and the vegetable. I am not alone and unacknowledged. They nod to me, and I to them. The waving of the boughs in the storm, is new to me and old. It takes me by surprise, and yet is not unknown. Its effect is like that of a higher thought or a better emotion coming over me, when I deemed I was thinking justly or doing right.

Yet it is certain that the power to produce this delight, does not reside in nature, but in man, or in a harmony of both. (pp. 8–9)

Geoff’s description of his spiritual feelings towards music also included a mixture of deep and intense feelings such as awe, esthetic feelings, and a sense of connection and deep understanding, whereas his feelings towards his guardian angel included, among others, feelings of being cared for, and being loved and connected. In all three cases the emotional experiences appear to be more profound and intense than usually encountered in the psychological literature on emotion (for an exception, see Keltner & Haidt, 2003).

Two participants (Geoff and Jimmy) also referred to their meta-emotions (e.g., “Anything new scares me—I hate that” [Jimmy]), which is, as previously reviewed, thought to be outside of autistic individuals’ capacities. Finally, one participant (Alan) made several references to mixed feelings (bitter-sweat, and guilty pleasure).

Taken together, this study’s participants’ understanding of their emotions is at odds with the stereotypical view of emotions as being “uncharted territory” for autistic individuals (Attwood, 2006, p. 130), or being less complex than those of others, as well as being something they cannot reflect on (de Vignemont & Frith, 2008; Hill et al., 2004). Most participants not only labeled and described many emotions, but they also distinguished between different intensities of the same emotions and between the same emotions in different contexts. They also described many complex emotions and did so in a way that suggests either an appropriate or—in several cases—
high level of understanding of emotional experiences. Indeed, only 1 participant could be said to have communicated only the most general emotional understanding, to which Barrett (2004) refers as “low emotional granularity.” However, as Barrett’s research indicates, many non-autistic (i.e., typical) people are also low in emotional granularity. Therefore, the participants’ differences in understanding their emotional experiences are consistent with typical individual differences in emotional granularity.

It is also important to note that in addition to showing relatively good emotional understanding, the participants’ descriptions of their emotional experiences also indicate that their emotional lives are much richer, deeper, and more intense than the existing accounts of autism suggest.

9.3.5.3.1.3 General Remarks about Self-Understanding of Other Participants

Howard. Although Howard’s self-understanding appears to be at a relatively lower level than that of the other participants, it is not clear how much his relative lack of self-knowledge stems from not understanding himself and how much from not engaging in the task of reflecting during the interview. As previously described, he refused to engage in remembering and thinking about his negative experiences. However, what he did say about himself, for the most part seemed appropriate and internally consistent: his descriptions of himself appeared in accord with his self-presentation; his statements were, for the most part consistent; and he was able to report the subjective meaning of those life experiences that he did share.

Sarah. Sarah demonstrated a relatively good, although somewhat black and white, understanding of herself. What is most interesting about her account is that a great deal of what she said about herself seemed to be a simple repetition of what others had said about her (as opposed to being a result of self-examination). For example, her self-descriptors (i.e., organized, reliable, and sweet) more resembled third- than first-person descriptors, as did some of her supporting statements. For instance, she said that she is an organized person because, among other things, she “keep[s] on top of things,” which sounded like a typical third-person praise. In fact, when talking about being a reliable person, she herself said, “Usually people tell me that I am reliable.” Likewise,
when elaborating on being a “sweet person,” she noted, “If I would say something that’s nice, usually people would say, ‘Oh, that’s very sweet,’ or something like that.”

Also third-person-like were Sara’s repeated uses of the words normal and happy to refer to herself, such as in the following examples: “I feel like I am normal as everybody else, which I am, like, I try to live a normal life as everybody else”; “I’m happy the way I am”; “I’m happy with the way I am”; and “I think I am already beautiful the way I am.” Likewise, many of her self-statements were more outside- rather than inside-oriented. Here is one example:

S: I guess what I like most about myself is that I enjoy life.
L: Okay. Can you say more about that so I know what you mean?
S: Well, I am enjoying life as it is right now.
L: And what are the most enjoyable aspects of your life right now?
S: That I’ve changed school. I have great family, nice friends, two jobs, loving environment at home.

However, when asked what her life would look like if she could choose to live another life, she admitted, “I think if I am living another life, I would be living it without maybe my disability,” which sounded more like a first-person answer than her other answers. In fact, this is the only time during the entire interview that Sarah had said that being autistic is not so “normal” as she was telling me for the rest of the interview. One way to explain this discrepancy could be that the question itself was new to Sarah, and she did not have a ready-made answer (i.e., aided by others), thus having to respond by telling how she really felt about being autistic.

**Jimmy.** Jimmy’s self-understanding is best characterized as uneven. He appeared to have a fairly good understanding of himself as a person at the general level; however, he had a lot of difficulties remembering specific experiences to support his self-generalizations. Despite not having many specific autobiographical details to work with, he made the most of what he could remember. His self-understanding provides a good contrast to Sarah’s as it demonstrates what an independent reasoning about the self could look like. Thus, although he, like Sarah, also considered himself an “organized person,” he did not mention it until he was asked about how other people would describe him. He said that “anyone that know[s] me—my bosses, my mother” would say that. However, being an organized person was not among Jimmy’s first five
self-attributes, suggesting, perhaps, its lesser personal importance. Moreover, unlike Sarah, he had much more to say about what it meant that he was an organized person than other people:

I like things to be, sort of, a certain way, and I think to, sort of, look a certain way, things like that. I tend to bother people with a . . . [sighs] you know, if you’re watching a movie, the way that the TV looks, how things are set up, how they look, or how the [chuckles] . . . you know, how they sound—I always want things to be as good as they can be, and if they are not, I go bug people about it.

When asked about his own things, he said it depends: “At work, I’m extremely organized. At home, not so much,” and explained:

Certain things, like, I mean, everything in my cupboard will have the labels facing out—things like that. I like my book shelves to all look a certain way—all the books to be biggest to smallest—that kind of thing. But, you know, I can still be messy as far as leaving clothes laying around—stuff like that. That doesn’t really bother me, but.

Jimmy showed the same kind of reasoning with regard to what he meant by being an open person: in some contexts he is open, in others he is not.

**Mike.** Like Jimmy’s, Mike’s self-understanding seemed entirely the result of his self-reflection. For example, he defined himself according to his worldview—according to what is most important to him. He said, he is a hard-worker because he has been working hard his whole life, and he has been working hard for everything he has achieved. “It’s my only thing I know,” he said, based on his examination of his life. Mike’s second defining feature was that he “try[s] to be good to people,” which is his only way to keep the relationships he has and (perhaps) develop new ones, and that is extremely important to him. Thus these two features clearly define Mike from his own perspective as well as give an impression that Mike has a good understanding of who he is.

However, Mike also said that he does not understand himself—at least, not as much as he would like. Despite its explicit acknowledgment to the opposite, I believe that this statement does not suggest lack of self-understanding in a usual sense. Rather, I believe it suggests the enormous difficulty inherent in an atypical human being’s task of understanding the difference between oneself and others. No matter how deep Mike’s understanding of himself is, it may always seem
insufficient whenever he attempts to apply his knowledge of himself to others. Such is the difference between them that what he finds good and desirable, others do not. However, Mike has also realized that his strategy of being “good to people,” who are so much different from him, does not lead anywhere (or at least not where he wants to get) and has recently changed it: he is now looking for people who are more like him (e.g., who have similar interests), and he hopes that this may be a better approach to establishing more meaningful relationships. All this suggests that Mike understands himself rather well (he is fully aware of his needs, feelings, interests, and abilities, as well as his weaknesses) and is continuously trying to improve on this understanding (one example is his participation in this study, about which he commented at the end of the interview “maybe, I get something from it—my self-understanding”).

Further evidence of Mike’s good self-understanding is his keen awareness of what he knows and what he does not know about himself, or, more specifically, of what he has thought of before and what he did not (that is, his metacognition). One illustration of this awareness could be found in his explication of his relationships with his co-workers when he said,

> It is my lack of ability to wanna tell them to do something cause I don’t want to lose them as an acquaintance. I didn’t even think of that before, seriously. I don’t wanna lose them as a . . . they’re not really my friends, but they are my acquaintances.

This insight suggests Mike’s high ability to examine his life and draw conclusions based on this examination. This is nowhere better seen than in his view on autism: He would prefer not to have it (and everything he said during the interview is consistent with this sentiment): “It bites. It’s terrible. It’s not fun. It’s not good. It’s not a good place to be. I don’t wish it upon anybody.” His words seem genuine, and their choice seems to convey his feelings well. They also convey an independence of thinking: despite his advanced knowledge of current issues in autism, Mike did not accept the trendy view of autism as human difference (not a disability), and based his view on his feelings about what autism has brought him.

**Orville.** Orville also seemed to be an independent thinker and not much of what he said about himself, others, and the world seemed learned from others; even when it did, as in case of his view of autism as desirable, it was clear that he based his view on his own self-examination and his own value system. Despite the social difficulties that come with autism, he believed that if
others were more accepting, they would not matter. Although this is a “standard” neurodiversity view (of which he is well aware), it does not seem that Orville accepted it from others; rather he seems to have began believing it a long time ago. In fact, his whole life story is a testament of his unorthodox view of his difference as a “chronic social disability.”

9.3.5.3.1.4 Interpretive Summary

Like Pierre, some other participants in this study also seemed to have difficulties with retrieving specific autobiographical memories to support their self-statements as well as with answering questions aiming at uncovering the way they think about themselves; however, this was not true for all participants. Indeed, most participants in this study provided rich and detailed accounts of their experiences and gave an impression of a relatively good self-understanding. Moreover, several participants showed elements of what is in developmental literature considered high level of self-understanding—characterized by an ability to deal with contradictions about the self, to which Labouvie-Vief (1992) referred as “dialectical thinking.” For example, in addition to providing specific examples of why he considered himself an organized or open person, Jimmy showed the complexity of his self-reasoning in the way in which he treated the contradictory evidence: he was organized with things that mattered to him—but not with everything—and it still meant that he is an organized person.

In general, this study’s participants clearly showed that they can say more than just “something” about themselves as Hobson and colleagues (2006, p. 134) believe. They also demonstrated that self-understanding of at least some autistic individuals is both “deep[er]” and “thick[er]” than Hobson and his colleagues, as well as others, claim it to be. They also showed that contrary to Hobson’s (2002/2004) claim, their selves do not “float unanchored” (p. 210).

Finally, this study’s participants’ self-understanding seemed to contradict mainstream psychology’s view that incorporation of others’ descriptions of self is the main avenue of self-understanding (Harter, 1999, 2006)—the view known as symbolic interactionism and dating to Cooley (1902) and Mead (1934). Except for Sarah, whose many answers seemed adopted from
what she had heard others say about her, other participants seemed to have gained their self-understanding mainly through self-reflection.

9.3.6 Pierre’s Life Outcome and the Role of Intentional Personal Development in It

In many respects, Pierre seems to have become the person he wanted to be up to this point: an intellectual who have developed a variety of intellectual interests, an art connoisseur, and a singer who continues to develop his talent. That seems to have been all\textsuperscript{41} that was important to Pierre until recently, when he realized that he would also like to have a social life outside family. In a follow-up interview Pierre said that he did not have any friends during his schooling, which lasted till he was 39 years old. It seems that he was so preoccupied with learning that he did not have time nor (mental) “space” for others and that it was only once after he finished his studies that he found space (and perhaps a need) for others. When that happened, Pierre started intentionally to engage in a variety of activities that he believed could help him become less asocial: attending social support groups for autistic individuals, going to Meetup groups, doing community work, posting his profile on the dating websites, learning to dance and so on. All this suggests that Pierre has been intentionally crafting himself according to his vision of what kind of person he wants to be.

However, Pierre’s version of the ideal person does not seem to quite coincide with that of the society in which he lives. Whereas for Pierre his education appears to be a goal in itself (getting a mastery of a subject, and thus transforming himself into \textit{cultural capital}; Bourdieu, 1983/1986), from the perspective of the society in which he currently lives, despite the explicit declarations to the contrary, education is mainly considered a means to obtaining a gainful employment, and when it does not aid it, no matter the mastery achieved, the person is not considered to have “achieved” in life. This discrepancy has important implications on how we are to judge Pierre’s intentional personal development as well as his life outcome up to this point. So when Pierre said that his most important goal is to obtain employment, and he is not

\textsuperscript{41} Although he did not talk much about it, Pierre also seems to have become a caring person. However, it is not clear how much this was intentional and how much a result of his upbringing.
even looking at the job advertisements, nor does he have an updated CV ready, we might be tempted to evoke his lack of will or intentional abilities. However, I believe that interpretation does not hold up under closer examinations of what Pierre’s intentions really are as opposed to those he expressed because he knows what he is expected to say.

When we evaluate Pierre’s life outcome, and the role of intentional personal development in it, it is also important to consider the effect that Pierre’s traumatic childhood experiences could have had on it, as well as the effect of the absence of any—professional or otherwise—help for almost four decades. Although it is not possible to know whether and how his life could have been different were he not bullied, it is important that we keep this question in mind when we consider his outcome as well as the outcomes of other autistic individuals who had similar experiences.

Asperger (1944/1991) wrote of autistic individuals that “they are full of surprising contradictions which makes social adaptation extremely hard to achieve” (p. 83). Pierre seems to be a perfect illustration of this contradiction: he possesses many talents and skills (across several domains) but is unable, or unwilling, to use them to make a living. However, although up until now Pierre was not able to capitalize on his strengths in terms of gaining income and living independently, it is obvious that he derives a lot of personal satisfaction from the use of his strengths for leisure activities. Moreover, he continues to develop his skills and abilities and to use them to enrich the lives of others through various volunteer and family engagements. From this perspective, and by virtue of not taking away from, or harming, others, he must be considered a valuable and contributing member of society. Thus, I believe, the case study of Pierre clearly illustrates that the criteria for a good life outcome used in autism literature—that considers only one type of contributions (i.e., economical productivity) as socially valuable and other kinds (such as cultural, intellectual, and other personal accomplishments) as unimportant—is inadequate.

Indeed, from the life-span perspective on human development, which argues that “adaptive development is reflected in whether and to what extent individuals attain, extend, and maintain performance at their personal optimum in domains selected for growth or effective functioning” (Maciel, Heckhausen, & Baltes, 1994, p. 61), Pierre’s life outcome must be considered a successful one.
9.3.6.1 Other Participants

**Mike.** Mike, who has full-time employment, a family, which includes two children, and a house, achieved his current life status by a combination of factors which, among others, include support from his parents, a “relatively” lucky choice of a military career (which provided stability to his life), and his intentional personal development. The latter was evident from his use of his self-understanding of his strengths and weaknesses when choosing a military career, as well as when choosing his partner through a dating agency. However, despite achieving what from the third-person perspective appears to be a good life outcome, Mike does not believe so because he is not accepted by others and is not happy.

**Howard.** Howard, who has full-time employment and lives fully independently in his condominium, seems to have achieved his current life status due to factors that, among others, include a generous and continuing support from his parents, support of his teachers, as well as his intentional personal development. Some of the areas of intentional personal development include conscious control of his behavior (e.g., not talking to himself in public but doing so in private), gaining social skills (by attending autism support groups) and gaining employment skills beyond those obtained through regular education (by attended specialized training courses for autistic individuals). Howard did not consider having a family as a necessary ingredient of a good life, and, consequently, did not make any efforts towards it. He was satisfied with himself and with his current life. He drew this satisfaction, at least in part, from comparing himself now to where he was before and seeing that he accomplished more than many who knew him ever expected he would.

**Sarah.** Although Sarah—who is the youngest of all participants; age 25—did not have a full-time job at the time of the interview, she did obtain one by the end of this study. And although she has not yet achieved full independence—which, given her age, is understandable—all evidence suggests that she is on her way to achieving it. She believed that “having friends, accomplishing school, and having a nice family life” were main ingredients of good life, and having all of them, she was satisfied with her life. Like Howard, she also based some of her satisfaction with herself and her life in self-comparisons, that is, in comparisons of herself now to herself when she was younger. Like Howard, she also credited her parents for her life success.
so far; however, there was also evidence of some contribution of her conscious effort. For example, in addition to gaining regular education qualifications (she obtained 2 college diplomas), like Howard, she also attended specialized training courses for autistic individuals, and also seemed to have improved her social skills as a result of attending several social skill building groups for autistic individuals. Finally, her intentional personal development was also evident in her continuous efforts to improve eye contact, which seems to be a particular area of difficulty for her. Although Sarah considered having a family a necessary ingredient of a good life, this was not one of her priorities at the moment, and she did not make any efforts toward it.

**Orville.** Orville—the oldest participant in this study and currently retired—in addition to living independently, believed that a good life should include good health, having relationships with others, including intimate relationships, as well as having some social influence. Consequently, despite achieving independent living for the most part of his life, and having good health, he was not satisfied with not having formed intimate relationships and not having any social influence. Although he achieved his independence in large part thanks to his conscious efforts at self-education in an area that suits his abilities, despite his earlier efforts at developing social skills as much as possible through reading relevant books and asking others for advice, he was not successful at developing his social skills to a level that would allow him to achieve intimate relationships and social influence. Moreover, it seemed that at some point in his life he stopped trying to learn any new social skills, believing that he has learned them to the extent that it is possible and that his failing to achieve intimate relationships and social influence is due to others’ nonacceptance.

**Geoff.** Although Geoff has been working and living independently for the most part of his life, he was not particularly satisfied with his life achievements. To paraphrase him, although he has been functioning well in the world, he did not feel well in it. He mentioned three reasons. First, he did not feel that he belongs—he did not “feel part of [the world]” and for the most part felt like an alien and an outsider. Second, he believed that he has significant creative abilities—in writing and music—and felt that only if he were working in an area where he could express these abilities, he would be happy. Third, he wanted to have good and loving intimate relationships, not just any relationships, which he had during his 8 years of unhappy marriage, and during other shorter relationships. Although he attributed his current level of “functioning” to his intellectual
abilities that allowed him to be a good student and obtain educational qualifications as well as to support from his parents, his account also contains evidence of his own conscious efforts to improve his life. They include his seeking professional help with regard to his difficulties and his efforts to continually improve his life through better self-understanding, one example of which was writing of his autobiography.

**Jimmy.** Although Jimmy worked and lived independently for the most part of his life, at the time of the interview, as well as at the end of this study, he was neither working nor living independently. He also did not have any significant relationships. On his own account, he was also depressed and suffered from social anxiety, both of which he supported by his other self-statements. Despite these additional psychological conditions—which are important to consider as potential contributors to his current life status and functioning—he is making continuous efforts to improve his life by (a) acquiring qualifications that would allow him to obtain a job that would meet his needs for expressing his creative abilities (which he believes he possess and for which he provided some objective evidence) and by (b) gaining a better self-understanding, which he believes is an important step toward improving his life. In addition to undertaking psychotherapy, he is also avidly reading about the lives of people with autism, hoping that their experiences will give him some important insights that he could use to improve his own life.

**Alan.** Alan is still working toward finding full-time employment and living independently, both of which he considered necessary for good life adjustment. However, when considering Alan’s achievements, it is important to remember that his behavioral difficulties associated with autism (i.e., his obsessive behaviors) appeared to be greater than those of all other participants. Therefore, to be able to evaluate Alan’s life achievement, as Howard and Sarah both realized, it would be most important to consider how much progress Alan made, not in reference to others (other participants, other autistic individuals, or other non-autistic individuals), but in reference to where he was before. Indeed, Alan too seems to have suggested the same thing when he said that being well adjusted meant learning new things. From this perspective, and in light of what Alan said—that he is continuously learning new skills and making conscious efforts at improving his life—it is reasonable to suggest that he has adjusted as much as he could. Given the continuing support from his parents, it also seems reasonable to expect that Alan will continue to improve his life.
Chapter 4 Discussion

This study was motivated by my desire to better understand autistic individuals better. I have spent many years working with autistic children and adolescents and found that the mainstream literature’s representations of these individuals—with some notable exceptions (e.g., Howlin, 2004)—did not coincide with my own experiential ones. These representations always leave me with the impression that something essential about autistic individuals is being left out—something that makes them a desirable kind of people, rather than the opposite, as the official representations hold. I believe that obtaining a “truer” picture of autistic individuals would be possible by focusing on the complex network of thoughts and feelings that make up the core of a person’s being—which Lewin called “life-space” (Lewin, 1939)—rather than attending only to easily controlled variables, which is the approach taken by mainstream psychology. I further believed that this aim could be achieved by integrating the following four psychological traditions. First, a person-centered tradition (sometimes referred to as an idiographic tradition; Allport, 1942; H. A. Murray, 1938; Rathunde & Csikszentmihalyi, 2006; Rogers, 1961; White, 1952) and a related “life-space” perspective (Lewin, 1939) focus on the “subjective” psychological world of the individual (p. 868), and are concerned with the present, past, and future of the individuals and the issues that are of central importance to them. Second, life-span psychology (Baltes et al., 2006) is concerned with human development across the life-span and with people’s adaptations to changing life demands. Third, positive psychology (Seligman & Csikszentmihalyi, 2000) focuses on people’s strengths and resources. Contrary to the core-deficit approaches to autism, a strength-oriented approach can reveal people’s resources that can be used as avenues for change. Finally, applied developmental science aims at applying the current understanding of human development to “the pressing human problems” (Lerner et al., 2000), as opposed to problems of theoretical (or academic) importance. Guided by these perspectives’ principles, I attempt to answer my 10 research questions, which I address in turn.

1. How do autistic adults describe themselves?

In contrast to the mainstream literature on autism, which defines autistic individuals in terms of their impairments (APA, 1994, 2000), and in contrast to other representations of
autistic individuals’ self-portrayals according to which they define themselves in terms of what they like and what they do (Attwood, 2006; Hurlbutt & Chalmers, 2002), most of this study’s participants defined themselves in terms of their personality characteristics: 4 did so exclusively, using terms such as hard worker, serious, introvert, organized, reliable, kind, intuitive, spiritual, creative, intelligent, and artistic; and 1 did so by selecting two (of three) attributes that were personality-related (i.e., intellectual, a dreamer/imaginative). Only 2 participants defined themselves mostly with reference to autism or potentially autism-related characteristics and behavioral difficulties (e.g., a “loner,” “obsessed with things,” “partly self-sustainable,” and having violent outbursts). Only 1 participant defined himself in terms of his likes (i.e., “sport fanatic,” “love to travel,” and “enjoy my job”). All participants’ self-definitions were consistent with their overall accounts as well as with their observed characteristics.

This pattern of self-definitions makes a significant contribution to the literature on autism. First, the participants’ self-definitions clearly suggest that we should modify our traditional definitions of autistic individuals—which define them in terms of their impairments—in a way that includes their personality characteristics, as well as their other strengths, as has already been alluded to by several autistic individuals (e.g., Holliday Willey, 2001; Grandin, 1995c; D. Williams, 1996a), and that would be consistent with Asperger’s (1944/1991) original account and, more recently, with Attwood’s (2006). Of particular significance are the participants’ self-characterizations that are usually assumed not to be descriptive of autistic individuals, such as being perceptive, understanding, and caring of others. Taken together with their descriptions that support such characterizations, their inclusion by this study’s participants suggests that it is possible that at least some autistic individuals possess cognitive-emotional capacities for social understanding usually not attributed to them. In any case, these descriptions necessitate further investigation. Furthermore, their self-perceptions as being nice and good to others, either for its own sake or in order to establish and maintain relationships, also point at a possible alternative characterization of at least some autistic adults.
2. How do autistic adults make meaning of their autism?

In their attempts to articulate how it feels to be autistic, the participants referred to unconventionality, thinking differently, “living in a bubble,” specialness, “brilliance and challenge,” awkwardness and unusualness, “trouble just processing social situation[s],” and having a label. All of these notions are consistent with autobiographical autism literature (e.g., Dumortier, 2004; Gerland, 1997; Grandin, 1995c; O’Neill, 1999; Prince-Hughes, 2004; Sainsbury, 2000; Sinclair, 1992, 1993, 2005; D. Williams, 1992).

All but one participant identified some positive aspects of being autistic. They include different thinking style (i.e., thinking outside the box, attention to detail, and three-dimensional thinking), good attentional focus, being honest, being good to people, and getting positive attention. However, the participants differed with regard to whether they think positive aspects outweigh negative ones. Whereas, in line with the neurodiversity view on autism (e.g., Sinclair, 1992, 1993; Holliday Willey, 1999; Lawson, 2000), 3 participants felt that being autistic is more positive than negative, other participants, either explicitly (3 participants) or implicitly (2 participants) expressed the opposite view, which is also the view of mainstream autism literature.

3. What are the most significant life experiences of autistic adults?

All participants selected at least one significant life experience from the category of personal development such as experiences related to life transitions (e.g., moving away from home and starting work; 5 participants); discovering their passions (e.g., music and photography; 3 participants); autism (e.g., getting diagnosed with autism; 2 participants); achievements (e.g., “the production of the [village] map”; 2 participants); spirituality (1 participant) and the Internet (1 participant). Six participants also selected traumatic life experiences, five of which were related to negative social experiences (e.g., being bullied; 3 participants). Lastly, three participants selected positive experiences related to social relationships: being married, living with a girlfriend, and starting to attend autism support groups. This assortment of experiences is largely consistent with autobiographical accounts of autistic individuals, which often include all of the more frequently mentioned
experiences of this study’s participants, such as being bullied (e.g., Gerland, 1997; Grandin & Scariano, 1986; Prince-Hughes, 2004; Sainsbury, 2000), getting diagnosed with autism (e.g., Dumortier, 2004; Lawson, 2000) and discovery of music (McKean, 1994; Robison, 2008; D. Williams, 1992).

The vast majority (75%; 18 out of 24) of the selected significant life experiences were positively valenced; however, negatively valenced, traumatic, experiences evoked more intense emotions during the interviews as well as appeared to have more dramatic consequences on the lives of the participants. Negatively valenced experiences were also selected from earlier memories; all but one negatively valenced experience occurred in childhood, whereas all but one positive experience was from adolescence (3) or adulthood (14; 78%). Finally, although most participants selected at least one negative life experience, the significant life experiences of 2 participants were all positive. Given the high incidence of depression in autism, and in autistic adults in particular (Ghaziuddin & Zafar, 2008; Sterling et al., 2008), these findings are surprising, as it is well known that depressed individuals have a negativity bias in remembering (Wisco & Nolen-Hoeksema, 2009). Although at some point in their lives most participants were depressed—several received diagnoses of clinical depression—at the time of the interview, only 1 participant was diagnosed as clinically depressed, although 5 were on antidepressants. It is then interesting and important that despite their emotional history, which very likely included an increased lifetime exposure to negative experiences as compared to those without autism, these negative experiences did not attain more central places in the participants’ life-spaces. This perhaps indicates that they possess high levels of personal strength known as resilience—which refers to people’s capacity to avoid negative outcomes despite the presence of significant risk factors (Masten, Best, & Garmezy, 1990).

Alternatively, a relative absence of depression in this study’s participants may indicate that they have developed coping strategies that protect them from “being psychologically harmed by problematic social experience” (Pearlin & Schooler, 1978, p. 2). Pearlin and Schooler defined coping as “a behavior that importantly mediates the impact that societies have on their members” (p. 2). According to these authors, coping could be exercised in three ways: by eliminating or modifying conditions giving rise to problems;
by perceptually controlling the meaning of experience in a manner that neutralizes its problematic character; and by keeping the emotional consequences of problems within manageable bounds. Several such mechanisms have been reported in the literature on coping with illness or old age when it is not possible to eliminate or modify one’s life conditions (Brandstätter, 2006, 2009; Pearlin & Schooler, 1978; Skinner et al., 2003). Some of the strategies that this study’s participants utilized involved changing the meaning of experiences in a way that neutralizes their negative character, controlling the emotional consequences of such experiences by avoiding thinking about them—as opposed to ruminating and self-blaming—flexible goal adjustments, accommodation (i.e., adjusting preferences to situational constraints; Brandstätter, 2006, 2009), downward and temporal self-comparison (A. E. Wilson & Ross, 2000).

An alternative, or, perhaps, additional explanation for this finding could be related to Csikszentmihalyi’s (1999) notion of autotelic experience or flow, which refers to highly absorbing and enjoyable experiences that people seek for their own sake. Indeed, all but 2 participants selected at least one of the experiences related to their special fields of interest as their most significant life experiences, whereas the 2 participants who did not select such experiences, did, however, talk about them during the interviews. Therefore, this study’s participants’ selection of more positive than negative life experiences as significant is consistent with the claim that they are autotelic persons; that is, persons who have autotelic experiences relatively often.

4. How do autistic adults make meaning of their life experiences?

Contrary to mainstream psychology’s view known as social constructivism (e.g., Fivush, 1991, 1994; Pasupathi, 2001), according to which we construct the meaning of our experiences in conversation with others, this study’s participants provide evidence that meaning making can be a solitary activity. In most cases, the meaning the participants solitarily constructed was similar to that which would be expected to be made in collaboration with others, and which is obvious even from the selection of the experiences chosen as being personally significant (e.g., moving away, getting married, getting diagnosed with autism, or “the production of the [village] map” and getting
accepted at the music academy). Indeed, the participants had no difficulty making meaning of their positively valenced experiences. The meaning of such experiences is constitutive of the experiences themselves; the experiences meant positive feelings because they met important needs of the participants, such as achievement (e.g., “the production of the [village] map”), social relationships (being married), or self-understanding (getting diagnosed with autism).

However, although the participants were also able to find personal meanings in their negatively valenced experiences, these interpretations were, for the most part maladaptive, and, in most cases, the participants were stuck with these interpretations for many years. For example, for all 3 participants who selected bullying as their most significant life experience, being bullied meant “there is something wrong with me” and “I’m no good.” Moreover, in all three cases these interpretations seemed to have further negative consequences (e.g., lack of self-esteem, depression, and/or physical illness). Further, 2 participants who were able to eventually re-interpret their childhood experiences during adulthood, seemed to have done it through a solitary activity, one of which involved writing about the experiences in an autobiography.

5. How do autistic individuals live?

Half of the participants in this study live fully independently. Although the other half live with their parents, only 1 participant seemed to require help, and that was minimal, with daily living activities. By the end of this study, half of the participants also held full-time employment whereas 1 participant was retired and 1 became unemployed only recently (he was employed for most of his adult life). The remaining 2 participants had held jobs for a less than a year each during their entire lives. These outcomes are in contrast to most outcome studies, in which only approximately 12% of high-functioning adults were employed full time (e.g., Barnard et al., 2001; Engstrom et al., 2003; Howlin, 2004). One way to explain this higher ratio of employment in this study is by the selectivity of the sample. That is, because the participants in this study were self-selected, it is quite possible that they are not representative of the whole autistic population. However, despite the higher ratio of employment in this study, it is important to note that none of
the employed participants held a job in his/her field of study, which is consistent with the literature (Attwood, 2006; Hurlbutt & Chalmers, 2004). It is, therefore, not surprising that most participants who were employed—either currently or in the past—also expressed dissatisfaction with their jobs.

Only 1 participant was married (at the beginning of the study but was separated by its end) and he also had children; 1 was divorced; 2 had had romantic relationships in the past; and half had never had a romantic relationship. (None of the participants had a romantic relationship at the time of the interview, but this changed for one participant by the end of the study.) None of the participants reported having a close friend. Although family relationships were the most important part of the social lives of most of the participants, all had at least some social relationships outside of the family. Half of the participants named three casual friends with whom they spend time in mutually enjoyable activities (e.g., watching movies, going out for lunches, celebrating birthdays together, talking, and communicating over the Internet). One participant had several “smaller friendships” or “loose associations” with people who let him “drop in any time.” Two participants had one friend each, and 1 participant (who was married and had children) did not have any friends. All but 2 participants were involved in group socializing (e.g., Meetup, sport and other interest clubs, and autism support groups). This pattern of socializing is largely consistent with autism research literature (e.g., Barnard et al., 2001; Engstrom et al., 2003; Howlin, 2004) as well as with autobiographical accounts (e.g., Dumortier, 2004; Edmonds & Beardon, 2008; Miedzianik, 1986; Shore, 2001). It is also interesting that all but one participant mentioned using the Internet for socializing purposes, 5 for socializing with strangers, which is also reported in autobiographical literature (e.g., Edmonds & Beardon, 2008; Shore, 2001).

In their free time, the participants reported engaging in a variety of activities related to their interests: intellectual activities (e.g., reading, researching, and solving puzzles); creative activities (e.g., writing, creating music, photography, and graphic editing); traveling, watching movies and sports, and being in nature. All but 2 participants also had active roles in their communities where they volunteer in various projects including singing, drama, office work, and fundraising. Of the 2 participants who were not involved
in any community work at the beginning of the study, one was involved at the end of the study and in the past, whereas the other expressed a high interest in such involvement but found it difficult to do so due to what he perceives as his communication difficulties. This pattern of activities is largely consistent with autobiographical literature on autism.

From the third-person perspective (here meaning my own), the participants’ descriptions of their daily activities and interest (in some cases almost life-long) and their nonverbal expressions during these descriptions, made me feel that the one thing that applies to all participants is that they are passionate people. Their passions encompass three worlds—physical, cultural, and social—and, among others, include music, photography, reading, traveling, nature, arts, writing, sports, politics, philosophy, maps, Meetup groups, and paranormal phenomena. In most cases, the participants’ descriptions of their involvement with their passions were reminiscent of Csikszentmihalyi’s (1990, 1993, 1999) notion of autotelic experience, or flow, which is characterized by an extreme level of concentration and joy. From this perspective then, I feel that as a group, this study’s participants could best be described as autotelic persons.

However, it is important to note that at least some of the participants’ passions would be characterized in mainstream literature as obsessions. However, I argue that there is no reason why they could not be labeled “passions” and thus clearly indicate strengths (or human capital) that need to be further cultivated (as opposed to being treated as symptoms that need to be eradicated). Indeed, there is no inherent difference between passions of well-known and well-admired great artists, inventors, and scientists, and passions of autistic individuals.

6. How satisfied are autistic individuals with their lives?

Except for 1 participant (one who was previously employed, lived independently, and had social relationships), all participants reported being relatively satisfied with their lives. Thus, two participants each rated their life satisfaction 5 and 4, out of 5; another 3 participants rated it as 3, and 1 participant rated it as 2. Participants who were employed tended to be more satisfied than those who were not. Among the reasons for their
satisfaction, participants mentioned being employed, independent, and healthy, and having family, relationships, a home, and engaging in leisure activities, all of which are also main ingredients of life satisfaction for non-autistic individuals (e.g., Cummins, 1996).

However, the participants largely differed in their subjective ratings of their social lives: they used six different ratings ranging from 1 to 5 (one rating included a half point). Of the ratings that were identical, two were at the middle point and two at 5. The participants’ ratings, for the most part, also differed from what would be expected based on the third-person perspective found in the literature on adult outcomes. For example, the participant whose social life from the third-person perspective would be considered at the highest level—because he was married, had children, and many acquaintances at work, and occasionally also socialized with his next-door neighbor and participated in two hobby groups (one of which was virtual)—rated his own socialization next to lowest of all participants (“1.5”). On the other hand, the participant who never had a friend outside hobby groups, nor a girlfriend, rated his social life as perfect—because it met his needs. These disparities point to an important factor that needs to be considered when we evaluate the outcomes of autistic individuals: how much their needs are met, not only how they compare with others. As both research and autobiographical accounts indicate, not all autistic individuals have the same social needs: some have higher (e.g., Dumortier, 2004; Holliday Willey, 1999; McKeen, 1994), others lower (e.g., Boswell, 2008; Grandin, 1992; Schneider, 1999).

Although Wing and Gould (1979) described autistic children’s individual differences in sociability, these differences and their implications for the life outcomes of autistic individuals are poorly understood. Therefore, this study’s participants’ descriptions of their social needs and their socializing patterns, along with their subjective evaluations of their social life, are an important contribution to the literature.

7. What does a desirable future of autistic adults look like?
All but one participant in this study would like to have a partner in their future. All participants who did not have full-time employment or were not living independently (4 and 3 participants, respectively) desired such outcomes. However, work-related goals were formulated very differently by the participants. Three participants wished for jobs that would, in addition to their financial needs, also meet their creative needs. Other desired futures included leisure activities such as traveling (5 participants), life enjoyment (3 participants), learning (2 participants; “going back to school” and learning to drive), moving (2 participants; to another city or country); social themes (helping other people, bringing up children, and “meet[ing] lots of friends”; 1 participant) and household duties (1 participant; “fix[ing] the house”).

These findings are in line with autobiographical accounts of autistic individuals, where the desire for relationships is often one of the most prominent themes (e.g., Dumortier, 2004; Edmonds & Beardon, 2008; McKean, 1994; Miedzianik, 1986; for some exceptions, see Boswell 2008; Grandin 1995c; Schneider, 1999) and where themes of work and independence are frequent among accounts of unemployed and/or dependent autistic individuals (e.g., Grant Lissner, 2000; Romoser, 2000; for an exception, see Miedzianik, 1986). Moreover, these desired futures were in line with those of non-autistic adults (Bybee & Wells, 2002; Cross & Markus, 1991; Hooker, 1999) in that they included developmentally-relevant tasks (i.e., socially constructed normative tasks) related to occupation, relationships/family, and independence; and personally-relevant themes such as learning, leisure activities, and household duties. As in cases of non-autistic adults (Brandstädter & Rothermund, 2002), their repertoires of the desired futures also reflected age-related changes.

The finding that the three most common desired futures were normative outcomes (i.e., social relationships, employment, and living independently) shows that at least some autistic individuals have the same visions of desirable life outcomes as nonautistic individuals, and that their not attaining them is not due to their lack of desire to do so. Given that, by definition, autistic individuals find social relationships undesirable or difficult, it is particularly interesting that all but one participant included intimate relationships in the repertoire of their desired futures. One participant’s absence of desire
for such relationships is also interesting because it seemed to stem not from autism per se, but from this participant’s coping strategy, which he adopted to protect himself from anticipated failure.

8. What would a “better world” for autistic individuals be?

Participants’ visions of a better world reflected their concerns for both self and others. Only 1 participant’s vision was completely self-focused. Other participants’ visions reflected their beliefs about a better life for (a) all people including themselves (e.g., a world without violence, market economy, or dress code); (b) all autistic people including themselves (e.g., a world where autistic individuals would be accepted as they are); and (c) only others (e.g., a world where everyone’s basic needs, such as those for food and shelter, would be met, and a world where an important aspect of schooling would include learning social skills). Such partly or solely other-focused visions are contrary to a prevailing view of autistic individuals as totally self-focused and unconcerned for others (e.g., Baron-Cohen, 2005; de Vignemont & Frith, 2008) but are consistent with autobiographical (e.g., McMullen, 2000), biographical (e.g., Jacobs, 2006), clinical (e.g., Attwood, 2006) and informal research observations (e.g., Baron-Cohen, 2005). Together with the participants’ other spontaneous remarks about being caring, understanding, and concerned for others’ wellbeing—including their feelings—these visions, then, provide some important evidence that challenges the traditional view of autistic individuals as totally self-focused (e.g., Baron-Cohen, 2005).

9. What are the perceived favorable significant influences in the lives of autistic individuals?

All participants identified their parents as having more or less significant positive roles in their lives, which was also consistent with their accounts when considered in their entirety. It is interesting that, in the majority of cases, this support did not seem to be outside the typical parental involvement in the upbringing of their children. Nevertheless, in the cases of participants who were diagnosed either before or during their early adulthood, parental involvement seemed to be above that of others in that it involved not
only persistence in searching for professional help—both in terms of explanation (i.e., diagnosis) and in terms of treatment—but also a significant amount of guidance in choosing a course of life. It is also interesting that 2 of these participants attained the life outcomes that would be judged as more successful by traditional criteria. The case of the third participant from this subgroup is particularly interesting because his current life situation seems relatively lower than would be expected on the basis of his intellectual abilities and the help he received, which included specialized individual and group interventions as well as a specialized vocational training. However, the level of his behavioural difficulties seemed to be greater than those of the other participants, perhaps indicating that the level of behavioural difficulty must be taken into account when considering life outcomes of autistic individuals. Although in their autobiographical accounts many other autistic individuals also acknowledged the significant positive roles their parents played in their lives (e.g., Barron & Barron, 1992; Grandin & Scariano, 1986; Purkis, 2006; Shore, 2001; Tammet, 2006), this was not always the case (e.g., Gerland, 1997; Lawson, 2000; McKean, 1994; Mór, 2007; Prince-Hughes, 2004; Robison, 2008; D. Williams, 1992).

Among other important influences the participants identified were relatives, teachers, and other professionals, as was also reported in autobiographical literature (e.g., Grandin & Scariano, 1986; Grant Lissner, 2000; Prince-Hughes, 2004; Shore, 2001; D. Williams, 1992).

10. How important is intentional personal development for the life outcomes of autistic individuals?

When the life outcome is traditionally defined—as being employed, living independently, and having social relationships—the role of intentional personal development did not seem to play as significant role in the outcomes of this study’s participants as has been previously suggested by Kanner and his colleagues (1972)—at least, not in the form they proposed. According to Kanner and his colleagues, the main determining factors of autistic individuals’ life success are enhanced self-awareness (including that of one’s differentness) and a conscious effort to change. Although all participants in this study
demonstrated relatively good self-understanding, only one participant seemed to have engaged in a conscious effort to change, and that participant, as yet, has not achieved “life success,” as defined above. However, it is important to note that the level of this study’s participants’ difficulties—behavioural ones in particular—did not seem to be as great as those of the individuals that Kanner and his colleagues followed up. Indeed, only the participant who was making a conscious effort to change his behavior seemed to have a comparable level of difficulty to the individuals originally diagnosed by Kanner.

However, although the participants did not reveal any dramatic changes achieved through their own conscious efforts (as is sometimes also reported in the autobiographical literature; e.g., Barron & Baron, 1992; Prince-Hughes, 2002, 2004; Grandin & Barron, 2005; Grandin & Scariano, 1986; D. Williams, 1994), most participants attained their current levels of success mostly due to their own efforts. This is particularly true for all 5 participants who were diagnosed in their adulthood.

Moreover, when the successful life outcome is defined as the attainment, extension, and maintenance of performance at individuals’ personal optimum in the domains they selected—a view advocated by the life-span perspective on human development (Maciel et al., 1994)—all participants exhibited significant intentional behaviour, which included selection of education, both formal and informal, and practice of learned skills—in paid or volunteer engagements and in leisure activities. Furthermore, all participants achieved high levels of personal excellence, for the most part, as a result of their intentional personal development.

10 Strengths and Weaknesses of the Study

This study has several strengths as well as weaknesses. They are discussed in turn.

*Strengths.* A major strength of this thesis is that it explored several aspects of autistic individuals’ self-perceptions from a temporal perspective. That is, it explored their self-understanding of themselves as persons, their emotional understanding, their understanding of
their past experiences and their implications for their current lives, and their desired futures. There are no other studies that have done that.

The second strength is that it explored a little utilized source of information about autism: autistic adults. As such, this study adds to a relatively small body of research that explored life experiences of autistic individuals. With some rare exceptions (e.g., Bemporad, 1979; Volkmar & Cohen, 1985), it is only recently that that the experiences of autistic adults have begun to be explored more systematically (e.g., Hurlbutt & Chalmers, 2002, 2004; Huws & Jones, 2008; Punshon et al., 2009). This study provides much needed descriptions of life experiences of autistic individuals in rich detail.

The third strength is its analysis of autistic individuals’ *self reports* and autobiographical documents—when available—which are rarely used in the study of autistic individuals. These data sources allow identification of new and potentially important dimensions of the lives of autistic individuals, which cannot be uncovered using theory-oriented and laboratory approaches. The use of this approach allowed for the discovery of a much richer, deeper, and more diverse “inner life” of autistic individuals, including their self-understanding and emotional life—and the understanding thereof—than is currently known. Also, contrary to the prevailing conceptions of the reliability of autistic individuals’ self-report, this study provided important evidence that at least some high-functioning autistic individuals can provide reliable and rich self reports, which are a virtually unutilized source of information in the study of autistic individuals.

The final strength I would like to emphasize is my utilization of available literature outside of what is typical for psychological research. More specifically, I used a significant amount of autobiographical evidence about autistic individuals from the already published accounts as a source of comparison with this study’s participants’ data and in support of data interpretations. In my data interpretations, I also used substantial amount of biographical and research evidence outside the clinical psychology.

*Weaknesses.* One limitation of this study is its *uneven treatment of the participants*. That is, whereas one participant’s data was treated in a intrinsic single case study design, all other participants’ data received an instrumental multiple case study treatment. Although it would be
preferable that each participant received the same treatment as the intrinsic case study participant, this was not possible to achieve in one study. Such treatment would require eight studies and would greatly exceed a reasonable number of pages for a project like this one.

Further two limitations come from the characteristics of the sample. First, a small number of participants limits the generalizability of the findings. However, this study was exploratory in nature and its main goal was to explore the lives and self-conceptions of autistic individuals in an exploratory fashion. I believe that this study’s sample was adequate to achieve this goal. Second, the use of a convenience sample (that is, participants responded to advertisements rather than being recruited randomly) further limits the study findings’ generalizability. Although thus-selected participants may not be representative of the whole population, the study’s findings could be generalizable to a similar population. Given the study’s exploratory nature, a convenience sample is appropriate as long as it is reasonably diverse, which was the case in this study. Thus, the participants varied in age (from 25 to 63 years), education (from a high school diploma to a PhD degree), geographical location (from a small town to a metropolitan city), employment (from being unemployed to being employed full time), gender (a male to female ratio 7:1, which is close the ratio of incidence of autism among high-functioning autistic individuals: 5.5:1; Fombonne, 2005), living arrangements (from living with parents to living independently), as well as in the level of severity of autism (from relatively more severe—within the category of high-functioning autism—to relatively mild).

To minimize the above limitations coming from the sample characteristics, as well as other potential limitations stemming from its qualitative nature, I used five validity procedures common in qualitative research. First, I provided all participants with both interview transcripts and the final study report and requested their feedback regarding the accuracy of their statements and my interpretations of them. All but 1 participant reviewed, commented on, and approved both the transcript and the report (6 participants: Mike, Orville, Alan, Geoff, Howard, and Jimmy) or the transcript only (1 participant: Pierre). Second, a peer, an autistic graduate student, reviewed the study report and provided his feedback. Third, I provided detailed descriptions of the participants and included extensive quotes from interview transcripts so that the reader can make an informed decision about whether the findings of this study can be generalized to apply to the reader’s particular situations to which they wish to apply them. Fourth, all data was
interpreted from multiple perspectives. Lastly, I outlined the potential sources of my bias (e.g., my theoretical, practical, and relevant personal background) in a Positionality Statement and employed just-reviewed procedures to minimize it.

Finally, although this study’s reliance on the retrospective data may be considered its limitation, asking people about their past experiences and their meaning making of them is the only way to study this aspect of self-understanding. Using other informants would not be of any help in this respect. As one participant (Orville) suggested, although many people have asked him why he is angry whenever he raises his voice, he said that he was not angry at all in those situations, but that that is his way of trying to make a point. As this example illustrates, in order to understand autistic individuals self-understanding, we simply have to ask them to tell us about their experiences and what they meant to them. Although real-time real-life meaning making is an important aspect of self-understanding, it is somewhat beyond typical research practices within psychology and would require an anthropological approach of being with autistic individuals, one at a time, for extensive periods of time. (Perhaps, this is something that should be done in the future.) Lastly, although in addition to using retrospective data, other more contemporaneous data sources such as intimate diaries (where people record their thoughts and feelings closer to the time they had them), autistic people seem to rarely engage in such practices. In fact, when one of the participants (Pierre) revealed his diary-keeping practices and offered his diaries to me to review them, I used this opportunity to corroborate his retrospective data whenever applicable.

11 Implications of the Study and Future Directions

This study provided preliminary evidence that suggests that autistic individuals, at least in their adulthood, have a better self-understanding (in all three areas examined: self-concepts, meaning making of life experiences, and meaning making of emotional experiences) than is currently contended in the literature. This discrepancy should be further investigated using both person- and variable-oriented approaches (i.e., group design), preferably utilizing longitudinal studies so that age-related change in this understanding could be examined across the life-span. A person-oriented approach could uncover the process by which autistic individuals get to understand
themselves in the absence of what is currently considered a necessary path—conversations with others.

This study also provided further evidence of a multiplicity of life outcomes for autistic individuals, as well as of developmental pathways leading to them. Although it does not lend direct support to the hypothesis advanced by Kanner and colleagues (1972) that intentional personal development is crucial for good life outcomes as they are traditionally defined, it does show that autistic individuals’ own efforts are crucial for their life satisfaction. Further studies are necessary to elucidate the “multifinality” (multiple ends from the same origin; von Bertalanffy, 1968) and the factors contributing to it. Utilization of both person- and variable-oriented approaches and longitudinal design are necessary for accomplishing this task.

One particular factor that seems to have played an important role in the participants’ life outcomes is their utilization of their strengths (e.g., attention to detail, three-dimensional thinking, and memory). In light of this finding, and given the relative paucity of evidence about the positive aspects of autism, it is important that the strengths of autistic individuals are explored more systematically in the future, as well as the ways in which these strengths could be further developed so that their utilization can be of greater benefit to society.

This study also showed that despite many negative life experiences and the continued stresses of daily life, at least some autistic adults maintained a positive outlook on life. Given the high prevalence of depression among autistic adults (e.g., Ghaziuddin & Zafar, 2008; Sterling et al., 2008), it would be important to find out the sources of such resilience and processes by which these individuals avoided becoming depressed. Given the lack of knowledge about coping strategies of autistic individuals, this should be an important area to be addressed in future research. Knowledge about coping competences would be particularly important for enhancing autistic individuals’ wellbeing and for the prevention of secondary problems such as low self-esteem and depression. Both person- and variable-oriented approaches and a longitudinal design are needed for this task.

All but one participant mentioned experiences of being bullied, with 3 participants selecting these experiences as being among their most significant life experiences. Given these
participants’ accounts of both short- and long-term consequences of these experiences, which are consistent with the literature on bullying (Rigby, 2003), and given the paucity of studies on bullying among autistic individuals, it is important to investigate this issue in a more systematic way. Within the context of the life outcomes of autistic individuals, it is particularly important to gain further understanding about the contributions of experiences of being bullied to the life outcomes of autistic individuals. Even more importantly, better bullying prevention programs should be developed and implemented to protect autistic individuals (of all ages) from this kind of experience as much as possible.

Although this study did not explore autistic individuals’ emotions per se and only their reports about their emotional experiences, these reports point to a possibility that autistic individuals’ emotional styles, capacities, and habits might be different than those of others. That is, their emotions might be different in, among other things, quality, intensity, scope, and directedness than the emotions of non-autistic individuals. Although similar evidence also exists in autobiographical accounts of autistic individuals, there are no studies that explored the emotionality of autistic individuals. Moreover, like autistic autobiographers, the participants in this study described some emotions that appear to be unique to them such as feelings of not being understood and accepted, feelings of living in another world, and autistic feelings. Therefore, exploring autistic individuals emotional experiences outside those they share with non-autistic individuals should be an important area of future research. A person-oriented approach is particularly well suited for this task of uncovering new kinds of emotions or their new dimensions in autistic individuals across the life span.

Finally, most of this study’s participants expressed their feelings of not being welcome in this world. That is, they felt as if they were living in two worlds: one theirs—autistic—which is a source of happiness, and one where everybody else lives but which is alien to them, and which is, for the most part, a source of unhappiness. They also described their largely unsuccessful attempts to build the bridges between these two worlds. It would be very important for the applied science of autism to come up with some ways to help autistic adults feel more at home in this world. To accomplish this task, we would have to engage autistic individuals more fully in research, perhaps as co-investigators, which is an approach already taken by some researchers (e.g., Gernsbacher and Mottron; see, for example, Dawson et al., 2007).
Chapter 5 Conclusion

This study did not provide overwhelming evidence for the significant role of intentional personal development in obtaining the positive life outcomes as they are traditionally defined—that is, being employed, living independently, and having social relationships—which was previously suggested by Kanner and his colleagues (1972), and which is sometimes also alluded to by others (Howlin, 2000b). However, this study did provide confirmation that intentionality is important for life outcomes defined as quality of life or life satisfaction, as well as for achieving personal excellence. As such, it provides some support for the idea that traditional life outcome measures are inadequate because they do not take into account individuals’ sense of satisfaction with themselves and with their lives, both of which this study’s participants have suggested are important indicators of a successful life outcome. In terms of other potentially important factors that influence the positive life outcomes of autistic individuals, the participants identified their parents, relatives, and professionals such as teachers and psychologists.

In this study, I considered several aspects of autistic individuals’ self-understanding: their conceptions of themselves as kinds of persons, their strengths and weaknesses, their awareness of their emotional experiences, their awareness and meaning making of their life experiences, and their visions of desirable futures. As would be expected in a nonautistic population, there were large individual differences among participants in the complexity of their self-understanding, but the accounts of all participants provided clear evidence that they understand themselves sufficiently to be able to use that understanding to navigate the world in a way that best suits their intellectual, emotional, and experiential realities. Even the two participants who could be judged as being low in terms of the sophistication of their self-understanding used their skills in a way that promoted their wellbeing (by navigating around the potential obstacles that seemed too big to overcome).

One particular observation about this study’s participants deserves special attention. Regardless of the level of success they have achieved from a third-person perspective, this study’s participants were all similar in one respect: they have been living their lives passionately, and they are able to draw significant life satisfaction from it. Indeed, as Csikszentmihalyi (1999)
argued, “People are happy not because of what they do, but because of how they do it” (p. 826, italics added). Moreover, if we accept R. C. Solomon’s (2008) view that living a good life means living one’s life passionately, it should be concluded that all participants also live a good life despite not obtaining what are traditionally defined as good life outcomes. Furthermore, the participants also live a good life by virtue of becoming cultural capital (Bourdieu, 1986) available for the rest of society to utilize as best it can; if society does not avail itself of this opportunity, we cannot blame autistic individuals for this failure. In addition to the ethical sense of a good life, the lives of most of the participants also had an esthetic dimension to which R. C. Solomon (1976) referred to as living lives as “works of art” (p. 431).

Finally, I believe that the word passionate is the word I was searching for in vain among mainstream representations of autistic individuals. That is, I believe that the participants in this study have shown that being passionate is one of their essential aspects. Indeed, their passion for order, beauty, and justice are—to use a socio-economic term (G. S. Becker, 1964)—their human capital. Autobiographical (e.g., Grandin, 1995c; Holliday Willey, 1999; Lawson, 2000; Prince-Hughes, 2004; Robison, 2008; D. Williams, 2003) and biographical literature (e.g., Dewey, 1991; Park, 1967) suggest that this could be true of many other, if not all, autistic individuals. As Asperger believed, and as Hegel (1832/1956) noted, “Nothing great in the World has been accomplished without passion” (p. 23; italics in original). Indeed, as Asperger (1944/1991) suggested, it is this very passion that makes autistic individuals the kind of persons that society should desire, value and welcome.
References


and social relationships: Adults speak out about Asperger syndrome (pp. 97–112). London: Jessica Kingsley.


APPENDIX A
Demographic Information Interview

1. Diagnosis
Have you been diagnosed with Asperger’s Disorder or high-functioning autism?
How old were you, approximately, when you received your diagnosis?
Have you ever been diagnosed with any other type of psychological disorders
(e.g., bipolar disorder, schizophrenia, ADD)?

2. Education
What is your highest level of education?
Did you go to regular or special classes? (If yes) When?

3. Interventions
Have you received any medical or psychological treatment for your autism?
(If yes) What kind? For how long? How old were you when you started this treatment?
Have you had any other treatments? Are you receiving any treatment right now?

4. Employment status
Are you employed at the moment?
(If yes) What is the title of your job or position? What is the nature of the work you do?
Is this work full time, half time, or less than half time?

5. Income
Describe your financial situation? Is it adequate?
(If not already answered) Are you receiving any disability benefits?

6. Marital status
What is your current marital status?
(If single, divorced, or widowed) Do you have a boy/girlfriend at the moment?
In the past?
(If in a relationship, current or past) For how long have you been in this relationship?

7. Family members
Who are the members of your family?

8. Residential status
(If not already answered) Do you live on your own, with your parents, with somebody else, or in a group home?
APPENDIX B
1. Current Self-Definitions

What can you tell me about the kind of person you are? (Probes: I want to know what you are like, what is most important to say about you.) (If more than 3 characteristics) Out of all these characteristics, which three do you consider the most important for you? Is the order in which you told me your characteristics also the order of their importance for you? (If less than 3 characteristics) What else is important about you? (Can you think of one more way to describe yourself? What else can you say about yourself?) (Probes about 3 characteristics) What does it mean that you are ___? (What does it say about you? Why is that important to say about you?) How did you come to the conclusion that you are ___ person? Have you always been ___? (If NOT) When did you become ___? How did you become ___? (If not clear) What has contributed the most to you becoming ___ person? Did somebody help you become ___? Who?

Now think about yourself one more time and see whether there is something else that would be more important to say about yourself than the three things you already told me? (Probes as above)

How do you think a person who knows you well might describe you? Who? Do you know of anybody who would describe you differently? Who?

2. Strengths and Weaknesses

What do you consider as your greatest strength? It could be one of the things you already told me about, or it could be something new. Why do you consider ___ your strength? Can you give me an example of a situation where you exhibited this strength? Can you give me an example of how you have used this strength?

What are some of your other strengths? (Probes as above)

What do you consider your greatest weakness? (Probes as above)

3. Current Self-Evaluation

What do you like the most about yourself? Why?

What do you like least about yourself? Why?

Would you say that most of the time you like or dislike yourself?

On the scale of 1 to 5, how much do you like yourself?

What have you considered when you said ___? (If not 5) What should you be like to deserve the rating of 5?

4. Intentional Personal Change

Have you ever thought of changing something about yourself that you do not like? (If YES) What? Have you ever tried to change it? (If YES) How? What happened? What was most helpful? Have you tried to change any other things about yourself? (If NOT) Why not? Do
you think ___ can be changed? Do you think people can change? Do you think you could change yourself?

5. Being Autistic

When was the first time that you realized you were different from others? How did you come to that realization? How did you feel then? How did you deal with it? What was most useful in dealing with this realization? Is there any particular person that you can remember that helped you deal with it? How do you feel about it now? What do you think about it now?

How did it happen that you got to be diagnosed? How did you feel when you got diagnosed with autism? What did it mean to you? What did you think about it? Did getting the diagnosis influence your life in any way?

What is it like to be autistic?

What are the most difficult aspect of autism to deal with? How do/did you deal with that? What was most helpful in dealing with ___? Who, if anybody, was most helpful in dealing with ___?

(If not covered above) Many autistic people find it difficult to deal with some aspects of social life, do you? (If YES) What is most challenging about social life? How do you deal with it? What was most helpful in dealing with ___? Who, if anybody, was most helpful in dealing with ___? (If not covered) What is your social life like now? Are there any people you consider your good/close friends? Tell me a little bit about your friends. (How did you met them? How often do you see them? What do you do together?) Are any/all your friends autistic? What is most enjoyable about your current social life? Did you get any help in dealing with social life / professional or not? (If NOT) Would you like to get any help?

On the scale of 1-5; how would you rate your current social life?

Many autistic people find it difficult to deal with rituals and obsessions, do you? (Probes as above)

Are there any good things about being autistic? Anything else?

What would life be like if you were not autistic? Would that be better, worse or the same to you? Why?

6. Psycho-social adjustment

Do you consider yourself well adjusted to the world or not? On a scale of 1-5, how would you rate your current adjustment? What have you considered when you said ___? What factors do you think should be considered when we talk about people’s adjustment to the world?
Do you know whether other people consider you well-adjusted or not so well adjusted? Do you know anybody who considers you [the opposite]?

7. Current Life-Evaluation

How does your day-to-day life look like? What do you like doing?

In general, how satisfied are you with your life? How do you feel about your life nowadays? On a scale of 1-5, how would you rate your life satisfaction? What has contributed most to your life satisfaction (or dissatisfaction)? What should your life look like for the rating of 5?

(If applicable) How satisfied are you with your current employment? On a scale of 1-5, how would you rate your current employment status? What should your employment look like for the rating of 5?

Are you involved in any type of community (volunteer) work? On a scale of 1-5, how would you rate your community involvement?

How satisfied are you with your current financial situation? On a scale of 1-5, how would you rate your current financial situation?

Past Experiences

8. Past Self-Definitions

You’ve been telling me about the kind of person you are now—were you the same kind of person 5 years ago? (If the same) How about 10 years ago? What were you like ten years ago? Were you ever a different kind of person? (If YES) When was it? What were you like then? How come you are not ___ anymore? (If different) What were you like then? How did it happen that you are not ___ anymore? What were you like as a child?

9. Significant Life-Experiences

Now, let’s talk about how you got to be the way you are now. You can try to imagine that somebody wants to write a nonfiction book or make a documentary film about you and this person needs to find out what events and experiences from your life—and from your perspective—are the most important to include in this book or movie—what experiences you consider to be most important in you becoming the person you are now. These should be the events that help you understand who you are as an individual and might be memories you would tell someone if you wanted that person to understand what kind of person you are. They should be events from your past that are still very important to you and help you define who you are. To help you reconstruct your life, it might be helpful to look at this imaginary life line and mark approximately the time when some important events happened and put a short label for these events, so you know what the marks are for—like one would put the titles for the chapters of the book about you. When you finish marking and labeling your life line, I will then ask you to tell
me a little bit more about some of those events, but for now, just list the main experiences, or memories from your life on this life line.

Out of all these experiences, which three would you consider to be the most important for becoming the kind of person you are now? (Probes) Can you tell me a little bit about [each of the three experiences]? (If not answered) What happened? How old were you then? How did you feel when this happened? How do you feel about it now? What did it mean to you? (What did you think about this event when this happened?) What does it mean to you now? What do you think about it now? Why is this event important for your life and for the kind of person you are now? How did it influence your life? If what you just told me had never happened, how would your life be different? What have you learned from this experience, if anything? Have you ever talked with other people about this event? (If YES) Who? Why? How did you feel when you talked about it? (Was talking about it a positive or a negative experience for you?) Would you say that talking to other people about ___ was in any way helpful to you? (If YES) How was it helpful? (If NOT) Why not? Did you ever want to talk to somebody about it? (If YES) Why didn’t you? So am I than the first person to whom you told about this? (If YES) And how do you feel now that you told me about this event?

(If not mentioned) When were you the most disappointed in your life? (Probes as above) (If not mentioned) How about the time when you were most unhappy; what made you most unhappy? (Probes as above) (If not mentioned) What is your happiest experience? (Probes as above)

From which of these experiences you told me so far did you learn the most? Can you think of any (other) experience from which you learned an important life lesson? What did you learn? (Probes as above)

What people do you consider to be the most important in your life? (Probes) Why is this person important? How would your life have been different without this person? Are there any other people that were important to your becoming the kind of person you are now?

10. Life Decisions

What is the most important decision you have made in your life? (Probes) How old were you when you made this decision? How did this decision influence your life? If you didn’t choose to___, how would your life have been different? How do you feel now about making this decision? In retrospect, knowing what you know now, would you make the same decision or a different one?

What were your other important life choices? (Probes as above)

Now, looking back over your whole life, if you had the opportunity to live it again, are there any (other) choices that you would make differently? Why would you like to make this choice instead of one you made then? (Probes as above)

11. Turning Points
Now, when you think about your life, do you find that there were any/any other events, or experiences, than those you told me about after which your life changed so dramatically that it felt like a different life from that point on? (If YES) Can you tell me a little bit about this event? What happened? (Probes as above)

Can you remember any other events that influenced your life in a dramatic way? (Probes as above)

Future Orientation

12. Future Autobiography

Till now you have been telling me about your life so far. Have you ever thought about yourself in the future? (If YES) Have you ever talked with other people about your future life? (If YES) Who? What did you talk about? (If NOT) Can you try to think about it now?

Going back to that book or movie about you, can you tell me some ways this book or movie about you might continue from this point on, and how it might end? (If obvious) That seems like a good/bad ending. Is that the best/worst ending? (If not obvious) Would you consider this a good or a bad ending? (If not mentioned) Where will you live? Who will be living with you? Who will your friends be? Will you have new or old friends? Why? What will you do together? What would you do for a living?

Can you tell me one more way that the book/movie about you could end? (Probes as above)

(Repeat the questions for the opposite type of ending)

How confident are you that you will gain the best possible life you have just described? How confident are you that you will avoid the worst possible life you have described?

13. Perceived Control over Future

On who or what does your future depend on?
How much will it depend on you? How so? Please elaborate.
How much will it depend on external circumstances? (Probes as above)
How much will it depend on other people? (Probes as above)

13. Projections for the Future

13. What goals do you have over the next five years? (Probes for the first 3 goals) How important is for you to ___? Do you have any ideas about how you can achieve this? What would you need to do for this to happen? What resources would you need in order to achieve this? What will be your first steps toward achieving this? When do you plan to start ___? What are some potential obstacles to the realization of this goal? How can you deal with ___?

14. Becoming a better person and living in a better world
If you could have three wishes, what would they be?

If you could choose to be any kind of person, what kind of person would you want to be?
Can you ever really become like that? How so? Why? Can you say more?
What could never change about you?

If you could choose to live another life, what would that life look like? (Probes as above)
What could never change about your life?

If you could choose to live in another world, what world would you choose?
How would that world be different from the one you live in now? (Probes as above)
If somebody asked you how this world, the world in which you live now, could be improved to
make it a better world for autistic people, what would you recommend?

Now I am going to ask you to think one last time about everything you have said today. Is there anything you would want to change or add before we finish this interview?

If I have a chance to continue this research in 5 years or so, to see how your life was in the next 5 years, and whether you achieved your goals, do you think you would want to participate again?

So far I have been asking you questions, but do YOU have any questions for me.

Thank you for participating in this study, and good luck with your life?
Life line of MIKE (pseudonym)

age    events

80
70
60
50
40
30
20
10
0

25 - 2nd child
32 - 1st child
27 - Joined Army
26 - Lost love
17.18 - Flying
6 or 78 - Bullied a lot
2 - French School
5 - Moved from Québec to Ontario
APPENDIX D
Transcription Conventions

Transcript Sample

L: First, I wanted to ask you, why did you decide to participate in this study?
J: [pen click] Hmm, well, [pen click] like I said, I was recently diagnosed, [L: Uh-huh.] and . . . so I am really kinda fascinated by the whole thing, and I really wanna kinda learn more about myself, and more about [L: Uh-huh.] all of it, and I thought this would be a good way, and hopefully, maybe, if it can help [L: Okay.] other people, help you, help whoever [L: Uh-huh.]—I am all for it.
L: Sounds good. Thank you very much, again, for coming. Now, I just want to tell you what we are going to do here today and next time. [J: Okay.]

Conventions

The interviews were transcribed verbatim except for some, but not all, false starts that I judged to be more interfering with smooth reading than contributing to understanding the participant; at the end, more false starts were retained than deleted. In addition, parts not essential to the interview, such as exchanges regarding the spelling of the words, the next meeting and the documents the participants needed to bring, were left out. In these cases, the exchange is described in square brackets (as indicated below).

Sounds:
- speaking
  - hesitation:             hmm
  - affirmative sounds:     uh-huh
  - negative sounds:        nn-nnn, neah
  - surprise:               oh
  - other sounds:           onomatopoeic (e.g., eee, ekh; hooohooo); or a description of how the sound is made (e.g., [tongue click], [clearing throat], [laughing], [sighing], [coughing])
- movement:
- environmental:
  e.g., [tapping], [shuffling papers]
  e.g., [knock at door]

Voice quality:          e.g., [softly], [sadly]

Tone of speaker
- very loud; yelling:    CAPITAL LETTERS
- much louder than preceding utterances: ↑ before the utterance
- less louder than normally:  e.g., [whispering], [in a low voice]
- less louder than preceding utterances: ↓ before the utterance
- trembling voice:        “ above the word (e.g., “I did nōt wānna gō”);

Speaker’s emphasis:      italics
Pauses
- pause of 1–2 seconds: [slight pause] – only when judged significant (e.g., “I’ve had one or two [slight pause] friends”; “it made me [slight pause] dislike myself”;
- pause approximately 2–4 seconds: [pause]
- pause approximately over 4 seconds: [long pause]

Recording is unclear
- if nothing is recognizable: [inaudible]
- if words could be guessed, the best guess: one or two options in square brackets (e.g., [said or set])

Additional or clarifying information
- if unclear from the transcript: information in square brackets (e.g., these people [people at work])
- speaker’s error: [sic] right after the word; or correct or omitted word, or words, in square brackets (e.g., “she” instead of “he” [he])

Cross-talk: [talking at the same time]

Listening acknowledgement and other utterances that do not interrupt speaker’s turn: put in brackets as they occur during another speaker’s turn preceded with the speaker’s initial (e.g., [L: Uh-huh.])

Contractions: typed as they are pronounced (e.g., I’d)

Reporting self-talk or what someone else said: quotes

Not completed thought: ellipses

Confidential or potentially identifying information: replaced with fictitious names or descriptions

Time stamps: inserted for every minute of the audio: [1]

Interruptions: e.g., [recording stopped and resumed after several minutes]
List of Emotion Words Used by the Participants

The initial list of names and categories was based on Shaver et al.’s (1987) list of emotion names, and the additional emotion names and categories are added from similar lists of other authors: Clore et al. (1987; marked by “c”), Fehr and Russell (1984, f), Johnson-Laird and Oatley (1989, j-l), Rozin and Cohen (2003, r) and Watson et al. (1988, w), as well as from other relevant literature (e.g., Cacioppo & Berntson, 1994, cb; de Sousa, 2008, d; W. James, 1902, j; Lutz, 1982, l; Scherer, 2004, 2005, sc; R. C. Solomon, 1995, so). The names that do not appear in Shaver et al.’s lexicon are italicized. (Names that appear in consulted emotion lexicons but not in the interviews are not included.) Emotion names taken directly from participants’ interviews are followed by an asterisk. The forms of emotion names are not always the same as those used by the participants; for ease of reading, all names were transformed into their noun forms. When the name used by the participants is not any of the syntactic forms of the name given, the actual name used is indicated in the notes. Square brackets indicate implicit feelings, which were counted separately. Emotion words used in response to questions that contain the same emotion word (e.g., wish, happy, disappointed) are not counted; that is, only instances when these words were used in relation to spontaneously remembered events were counted.

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\(^{l}\)Values in brackets are tentative due to missing data.
\(^{d}\)Values in brackets are tentative due to missing data.
\(^{*3}\)Doubt is a response to the question: "Do you feel...?"
\(^{*4}\)Feeling of getting somewhere is a response to the question: "Do you feel...?"
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<tr>
<td>(being) dis-/un-able (l)</td>
<td>x</td>
<td></td>
<td>[x]</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>[1]</td>
</tr>
<tr>
<td>wonder (c)</td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

**Esthetic feelings** (sc)

| esthetic feelings (sc)                           | [x]          | x | [x]| [x] | x |   |   | [x] | 2 [4] |
| love [of arts and nature]$^6$                    | x            | x |   | x | x | x |   |   | 5     |
| marvel (c)                                       | x            |   |   |   | x |   |   |   | 1     |
| [passion for creating]                           | [x]          |   | [x]|   | [x]| [x]| x |   | [6]   |
| [passion for order]$^7$                          | [x]          |   | [x]| [x]| [x]| [x]|   |   | [3]   |

**Ethic feelings**

| care/concern for others                          | x            | [x]| [x]| x | x |   |   | x | 4 [2] |
| [feeling of justice] (so)                        | [x]          |   | [x]| [x]| [x]| [x]|   | [x]| 7     |
| loyalty (f)                                      | x            |   |   |   |   | x |   |   | 2     |

**Spiritual feelings** (j)

| - towards a guardian angel/music$^*$             | x            |   |   |   |   |   |   |   | 1     |
| - toward nature$^*$                              | x            |   |   |   |   |   |   |   | 1     |
| Total (2)                                        | 0            | 0 | 1 | 0 | 0 | 1 | 0 | 0 | 2     |

**Mixed feelings** (cb)

| bittersweet$^*$                                   | [x]          |   |   | x |   |   |   |   | 1 [1] |
| guilty pleasure$^*$                               | x            |   |   |   |   |   |   |   | 1     |
| Total (2)                                        | 0 [1]        | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 2 [1] |

*(table continues)*
### Absence of feelings (m)

<table>
<thead>
<tr>
<th>Emotion words</th>
<th>P</th>
<th>M</th>
<th>O</th>
<th>S</th>
<th>A</th>
<th>G</th>
<th>H</th>
<th>J</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>“apathy” (c)</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>emotional coldness*</td>
<td>x</td>
<td>x</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>calm (j-l)</td>
<td></td>
<td>x</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(being) drained*</td>
<td>x</td>
<td>x</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>no interest (m)</td>
<td>x</td>
<td>x</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (5)</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Grand total (140) [6]</td>
<td>31</td>
<td>36</td>
<td>41</td>
<td>20</td>
<td>33</td>
<td>72</td>
<td>16</td>
<td>43</td>
<td>292</td>
</tr>
</tbody>
</table>

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1. Shaver et al.’s (1987) name for this category is *surprise*.
2. Geoff did not use any of the syntactic forms of the word *determination*; instead, he said, “I do feel driven to complete tasks.”
3. Rozin and Cohen (2003) used the word *skepticism*.
4. Geoff referred to this feeling twice. He said, “I feel like I’m getting somewhere” and “I feel like I’m getting to where I want to be.”
5. Feeling of knowing refers to a well-known experience of knowing something without being able to recall it, often referred to as one of the aspects of metacognition (e.g., Hart, 1965; T. O. Nelson & Narens, 1980); however, de Sousa (2008) has recently considered it as one of epistemic feelings, together with surprise and wonder, which have been considered feelings in many major classifications of feelings. Jimmy made many references to not being able to remember at the moment but feeling that he would be able to remember on another occasion, particularly if he were alone.
6. Love for people (from the first category of emotion words) and love for non-people (from the category of ethic feelings) are treated as one emotion word—having two objects.
7. This term covers Geoff’s mentioning of the importance of things being symmetrical: “In my writing, it was very important to me the structure of the book be very symmetrical,” Howard’s excited declaration, “I have an unbelievable filing system,” followed by a description of how he keeps everything in his home in order, Jimmy’s statement about his need to order books from the smallest to the biggest, and to put other things in other, and to the Alan’s explanations of his need for order, including when is the good time to take out the chewing gum.
8. The participants did not use the word *apathy*. They used “emotionless,” “emotional shutdown,” and “I’m quite comfortable to just sit in the chair and not do anything,” respectively. Geoff also said, “what I felt about myself was nothing. I didn’t feel anything about anything. I was shut down.”
9. The phrase “emotionally cold” was used by Pierre, whereas Geoff and Jimmy used the terms “frozen” and “closed off,” respectively.