Embodied, Intelligent and Empathic: Reframing Autism Using Insider Perspectives

by

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Rehabilitation Sciences Institute
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Abstract

**Background:** To date, academic and clinical conceptualizations of autism have been built on research that reflects the perspectives of researchers and scholars, to the exclusion of the perspectives of autistic insiders. **Objectives:** To build deeper understanding of autism, especially its associated characteristics and behaviours, by examining the perspectives of people who identify as autistic. **Research Process:** Adopting a descriptive qualitative approach, I conducted three sequential studies. In the first study, I used inductive thematic analysis of memoirs for an early exploration of insider perspectives and identification of phenomena of interest. Through this, I identified experiences of being misjudged and embodied autism as primary phenomena of interest. In the second study, I used directed content analysis of blogs to pursue a deepened understanding of embodied autism. In the third study, I used the dataset from Study #2 and applied inductive thematic analysis to the blog content to more closely examine insider framings of autism. **Results:** The informants in this research conceptualize autism and explain its characteristic behaviours in ways that are fundamentally different from the dominant framing of autism. When explaining their autistic behaviours and functional challenges, the informants highlight embodied issues such as difficulty controlling movements and maintaining an adaptive level of arousal. The informants frequently experience being misjudged and misunderstood and
express desire for a shift in the dominant framing of autism to better match their perspectives and needs as autistic insiders. **Conclusions:** Together, these studies offer an insider-informed framing of autism that is more embodied, intelligent, empathic, and positive than depictions of autism in dominant literature. This research highlights the feasibility of insider-informed autism research and its potential to enrich autism science and service.
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I would like to acknowledge the people who have made this pursuit possible. My peerless husband Stephen Cottrell has supported me in every possible way, being everything I need whenever I need it. I never met the boundaries of his patience, generosity or creative problem solving, which I think bodes well for the rest of our journey together. I must also acknowledge our remarkable children Malcolm and Esther Cottrell, who have had to be more mature, more independent and more selfless than I would have otherwise asked them to be. Together they have cheered me on and cheered me up throughout the entire process.

Pursuing my PhD was a new experience in many ways. One significant way was that it was my first experience in which non-family members put significant investments in me, giving time, advice, insight, endless coaching and countless letters of support. I have been truly humbled by this and have much to pay forward.

It is my very good fortune that Helene Polatajko has served as my thesis supervisor. I knew before working with her that she is a world leader in occupational therapy, pediatric intervention and rigorous research methods. It has never surprised me that she has a brilliant mind: agile, curious, non-linear. Nor was I ever surprised to witness her tireless dedication to her research and to the advancement of occupational therapy. I witnessed the care and thoroughness with which she approaches tasks and the long hours she invests, with admiration, but not surprise, because a person with her achievements could manage this no other way. The surprises that came with working with Helene were as follows: despite her status and unthinkable schedule, Helene was more available to me than my best friend in high school. She answered every email, including an emergency midnight-on-a-weekend-need-a-signature-or-I-won’t-get-this-grant-email (didn’t get the grant anyway, but Helene never complained). Helene built me up and reigned me in as needed. She challenged me, inspired me, made me think until my head hurt and then made me think some more. There is no other advisor who could have made this work as solid or could have made me grow so much. I look forward to continued mentorship from Helene and I will work to retirement and beyond to make her investments worthwhile.

There is no question that without Patty Rigby, I would not have pursued doctoral studies. Patty was first my professor in the occupational therapy program (U of T class of 2001) where she gave excellent lectures and managed to support and inspire 60 of us at a time. She also served as
my academic advisor, a role in which she always gave me great advice. Still in the OT program, Patty was my undergraduate research supervisor and she gave me very a satisfying introduction to research. I continued to seek out Patty as a clinical mentor over the years and in 2008, she invited me to do my first lecture in the OT program, which grew into frequent engagements in the program and became an important part of my contributions as an OT. It was Patty who eventually suggested I pursue doctoral studies. Her confidence in me (and her first of many recommendation letters) helped me gain acceptance to the MSc program and then to transfer to PhD. Without Patty’s inspiration, advice, encouragement and endless reference letters, I would not be here today. Perhaps most amazingly, I am only one of many people in this field who attribute most of the advancements in their careers and academic pursuits to Patty. She is truly an inspiration to many.

Margaret Fitch served as a member on my advisory committee and was exactly who we needed to help guide this work. Her expertise in qualitative methods has proven invaluable from start to finish. Her calm nature and grounding presence as well her breadth of understanding pertaining to the theoretical and practical considerations of qualitative health research have contributed immeasurably to the quality of this work and to my own mental health when I became lost in theoretical quagmire, or the enormous responsibility and complexity of amplifying insider voices while speaking to a health sciences audience.

Deb Cameron was a late addition to my advisory committee, who stepped in when needed despite tremendous other commitments, including helping another doctoral student finish within a week of me. Despite joining in the final few months, Deb put in a great many hours into this dissertation. Deb’s input has been insightful, constructive, specific and very helpful, with just the added touch of encouragement I needed. I am so very grateful for Deb’s help.

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Chapter 1
Introduction and Background

1 Introduction and Background

“I write and speak to Autistic adults, in solidarity and with the message that you are not alone and you are not broken, and to family and mentors of Autistic children, because I don’t want the children of today to spend tomorrow going through the things I lived through yesterday.” (Sparrow, 2018)

1.1 Introduction

The introductory quote above comes from a blogpost within one of the datasets used in this thesis. It is a peek at the compelling autism-insider (a person who identifies as autistic) perspectives presented in this thesis and alludes to the major themes that will be discussed. The insider perspectives offered in this thesis were gleaned from a series of extant texts which were studied using qualitative methods designed to shed light on the experiences and insider-framings of autism. In this chapter, I offer an overview of the thesis and a discussion of the important terms used within. I then discuss literature relevant to the way autism has been understood and framed over the past seventy years, with emphasis on current framings. Next, I present an argument that current understanding of autism requires advancement. Finally, I present a statement of the research problem driving this thesis work.

1.1.1 Thesis overview

This is a manuscript-based thesis, formatted using a template from the School of Graduate Studies at the University of Toronto. In this first chapter, I provide an introduction and background to the topic of research as well as an overview of the thesis. In the second chapter, I give detailed descriptions of the methodology and a high-level overview of the methods used in the studies conducted for this thesis. In Chapters 3, 4, and 5, I present the results of three sequential studies, each in a manuscript format. See Figure 1-1 below for the flow of the three studies over the results chapters. The manuscript comprising Chapter 3 is published in the journal Disability and Rehabilitation (Welch, Polatajko, Rigby, & Fitch, 2018) and reports on
the findings from the first study, an inductive thematic analysis of memoirs written by autistic youths. In Chapter 4, I present a manuscript that has been prepared for submission to a peer reviewed journal. It reports on findings from the second study; a directed content analysis of blogs written by autistic people. In Chapter 5, I present a manuscript that has been prepared for submission to a peer reviewed journal. It is a report on findings from the third study, an inductive thematic analysis using the same dataset from Study Two, which had been generated from blogs. In Chapter 6, the final chapter, I offer a synthesis of the key findings across the three studies. I then discuss the significance of this research from a rehabilitation perspective. I conclude the chapter with a discussion of knowledge translation strategies for this body of work, the limitations of the research and final conclusions.

Figure 1-1 Flow of research

1.1.2 A word about words

1.1.2.1 Identity/person first

It has been argued that disability is a form of diversity, and rehabilitation professionals must develop and maintain cultural competence regarding disability and the language used to describe it (Dunn & Andrews, 2015). It is also known that language can influence thoughts and
behaviours towards individuals and groups in both daily life and clinical settings (Dunn & Andrews), so serious thought should be given to choices in vocabulary. People with disabilities will have varying perspectives on language, which makes it important for researchers and clinicians to have flexible, working knowledge to guide our use of language (Andrews et al., 2013).

The American Psychiatric Association, as well as most rehabilitation journals, advocate the use of person-first language (APA manual, 2010; Dunn & Andrews, 2015). The intent is to demonstrate respect for people by acknowledging them as people first rather than highlighting their disabilities or illnesses (APA manual). As a rehabilitation professional immersed in this way of thinking, I have used person-first language in my writing and speech for as long as I can remember. However, the second and third studies of this thesis used blogs as the data source and, as I engaged with that data, I found that the bloggers were engaging in explicit discussions on this topic. Many blog posts within the dataset were advocating identity-first language and promoting terms such as “autistics” and “autistic people”.

Kenny and colleagues (2015) surveyed 3,470 people from the autism community in the United Kingdom. Respondents were autistic adults, friends, family members and professionals. This largescale study found a range of perspectives on preferred language, particularly pertaining to person-first vs. identity-first language, with no universally accepted opinion. Professionals reported a preference for person-first language while autistic adults (and some parents) preferred identity-first language.

Despite the widespread use (and frequent insistence upon) person-first language in academic literature, not all academics advocate for this practice (Dunn & Andrews, 2015; Gernsbacher, 2017; Kenny et al., 2015). Several scholars within the disability studies field view identity-first language as a positive way for groups to experience pride, autonomy and agency and have found person-first language to be well-intended but ultimately ineffective in reducing stigma (Dunn & Andrews; Gernsbacher).

The debate on person-first vs. identity-first language demonstrates that this is a complex issue. In response to this complexity, Dunn and Andrews (2015) suggest that scholars use both identity-first and person-first language, suggesting that which term one uses may depend on the intended audience and their perceived preferences. Kenny and colleagues (2015) also promote an ongoing,
flexible and thoughtful approach to choosing language in the context of autism and disabilities. Their findings indicate that terms people use vary according to complex multiple factors such as people’s beliefs about autism and their individual contexts. In an especially flexible approach, Dunn and Andrews add that it can be useful to use both terms alternately within one piece of writing to acknowledge the duality and complexity of the issue.

For this thesis, I have chosen to use language in a manner that is consistent with its source - that is: I use person-first language when quoting or paraphrasing literature that uses person-first language. When reporting on the findings from my data and all other times I use identity-first language. The exception is Chapter 3 - which is a manuscript already published in Disability and Rehabilitation. This journal requires use of person-first language and there I use person-first language only. I write in this flexible way as I believe it to be aligned with the wishes of most of the memoirists and bloggers whose writings form my datasets, as well as autistic members of the public who I hope will someday read this research. This also fits with the descriptive qualitative approach employed in this research, which values language and terms that come from the informants themselves (Bradshaw, Atkinson, & Doody, 2017).

1.1.2.2 Neurotypical, non-autistic

Throughout this thesis, I use the terms “neurotypical” and “non-autistic” to refer to people who do not identify as having autism. These terms were generated by autism self-advocates (autistic people who work to promote autistic peoples’ rights and autonomy) to help define autism and the absence of autism on their own terms and to remove the word “normal” from narratives pertaining to autism (Nolan & McBride, 2015). They are also the terms used most often within my datasets by autistic writers when referring to non-autistic people.

1.1.2.3 Neurodiversity

Neurodiversity is a nuanced and controversial concept. There are two central components to the concept of neurodiversity: the first is the idea that autism is foremost a natural variation in normal neurological functioning (Jaarsma & Welin, 2012). The second is that autistic people should be conferred the same rights, dignity and worth as people who do not have autism (Jaarsma & Welin).
1.1.2.4 Framing

In this thesis, the term “framing” is used to refer to an overall schema or set of basic ideas attached to a phenomenon (Shefrin & Statman, 2000). One phenomenon can have several different “frames” built around it according to different perspectives (Shefrin & Statman). Frames are important in rehabilitation because they draw attention to certain aspects of a phenomenon while excluding or underemphasizing other aspects (Fox & Aranko, 2017). Frames provide rationale for implementing various courses of action (Fox & Aranko). Framing is powerful and has been shown to have lasting influence on healthcare and rehabilitation practices, even when those practices have little evidence of efficacy, sometimes leading to long standing commitment to a faulty course of action (Fox & Aranko).

1.2 Background

1.2.1 Clinical framings of autism over time

In a rehabilitation context, it is important to consider the way autism has been framed over time, as it helps contextualize the current dominant framing of autism. Considering autism frames over time is also important because it highlights what Verhoeff (2013) calls the “provisionality and plurality of knowledge and truth about autism” (p. 455). Verhoeff identifies three “phases” that span three separate time periods and are characterized by three different framings of autism. In the following sections, I will discuss the three ways in which Verhoeff says autism has been framed over time. Considering the multiple phases of autism framing calls into question the stability of the present framing of autism and opens consideration for new framings.

1.2.1.1 First phase: Extreme autistic aloneness

The condition that we now know as autism was first formally described in 1943 by Austrian born child psychiatrist Leo Kanner (Amaral, 2011; Verhoeff, 2013). This inaugural phase in the conceptualization of autism originated with Kanner’s seminal paper in 1943 and spanned to 1960 (Verhoeff). Drawing heavily on Kanner’s work, the term “early infantile autism” was common during this phase and the condition was seen to be an early manifestation of childhood schizophrenia (Verhoeff). During this phase, autism was framed primarily as “extreme autistic aloneness and insistence on sameness” (Verhoeff). Kanner’s work framed autism as a psychobiological disorder which was both biological and psychogenic in origin (Verhoeff). It
was in this context that the now debunked “refrigerator mothers” theory (in which autism was purported to be caused by a failure of maternal nurturing), proposed by Bruno Bettelheim, was popular (Rajendran & Mitchell, 2007; Verhoeff).

1.2.1.2 Second phase: Perceptual and cognitive abnormalities

The second phase in autism framing spanned from 1960 to 1980 and portrayed autism as a cluster of language and other perceptual and cognitive abnormalities (Verhoeff, 2013). In this phase, autism was no longer considered to be related to schizophrenia, nor was it considered to be a disorder of social relationships. The social and behavioural characteristics of autism were seen as secondary consequences of the primary problem of language and cognitive impairments (Verhoeff). It was in this phase that the Diagnostic and Statistical Manual of Mental Disorders (DSM) included diagnostic criteria for autism for the first time, with these criteria matching this emphasis in language and cognitive deficit (Verhoeff).

1.2.1.3 Third phase: Deficits in social cognition and social instinct

The third phase described by Verhoeff (2013) began in 1980 and continues to the present day. It frames autism as a spectrum condition characterized by a cluster of “deficits in social cognition and social instinct” (p.454). Within this phase, two interesting concepts have emerged; both stemming from the work of influential autism researcher Lorna Wing (Verhoeff). The first concept presents autism as a triad of deficits in the areas of social, language, and behavioral functioning. In this framing, social impairment has become the central distinguishing feature of autism (Verhoeff). It has been in this phase that the work of Austrian pediatrician Hans Asperger, which also focused on social impairment, gained international attention (Verhoeff). Lorna Wing argued that the cases seen in Asperger’s work and Kanner’s work were essentially similar and from this, the concept of a spectrum disorder arose (Verhoeff). Asperger’s as a diagnosis has both risen and fallen in this phase and has been replaced with the concept of a spectrum disorder, no longer necessitating a separate diagnosis for individuals at one end of that spectrum (Carpenter, 2013; Verhoeff). The DSM 5 reflects both the spectrum concept and the triad of impairments concept (Verhoeff). An additional trend in the current phase is a shift from framing autism as a rare condition (estimated 40 years ago as 4 per 10,000) to a much more common one (current global estimates around 1%). (Rutter, 2007; Verhoeff).
1.2.1.4 Current framing of autism

Autism is currently framed as a highly heterogeneous neurological condition involving communication difficulties, repetitive behaviours and restricted interests (Anagnostou et al., 2014). It is believed to be caused by multiple factors, with genetic, epigenetic and non-genetic influences (Anagnostou et al.).

According to DSM 5 diagnostic criteria, a diagnosis of autism requires: deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors and deficits in developing, maintaining, and understanding relationships. These characteristics intersect with three levels of severity: requiring support, requiring substantial support and requiring very substantial support (APA, 2013). A diagnosis on the autism spectrum can be received at any age but must include a history of related characteristics in early childhood (APA).

While autism is understood to be a neurological condition, no specific neuroanatomical or neurochemical basis for autism has been identified (Verhoeff, 2015). The current understanding of autism is based on theoretical explanations for its observable characteristics. Multiple neurocognitive theories inform autism framing, the three most influential being Executive Dysfunction Theory, Weak Central Coherence Theory, and the Theory of Mind (TOM) hypothesis of autism (Rajendran & Mitchell, 2007).

Executive Dysfunction Theory purports that autistic characteristics can be explained by an executive dysfunction deficit. According to this theory, autistic behaviours are primarily explained by difficulty initiating, sustaining and shifting attention, poor flexibility of thought and action, as well as poor response inhibition (Rajendran & Mitchell, 2007). This theory has held intuitive appeal but has not stood up well in empirical testing. This is due to difficulty establishing executive dysfunction as unique to autistic people as well as difficulty establishing its impact on the population; with some studies showing difficulty for only half of autistic people (Rajendran & Mitchell).

Weak Central Coherence Theory (WCCT) purports that autism characteristics reflect weak or absent drive for global coherence (Rajendran & Mitchell, 2007). This implies that individuals with autism process elements of their environments in a way that is fragmented and hyper-focused on detail without processing the whole. While initial presentations of WCCT were of a
singular explanatory theory of autism, it has since narrowed its explanatory scope and is now presented more as a cognitive bias held by autistic people rather than a global cognitive dysfunction (Rajendran & Mitchell).

The Theory of Mind (TOM) hypothesis of autism purports that core autistic behaviours can be explained by autistic people’s decreased capacity to understand the mental states of themselves and others (Rajendran & Mitchell, 2007). Simon-Baron Cohen, who initially proposed the hypothesis, eventually modified his stance to suggest that TOM is not completely absent in autistic people, but that for autistic people it tends to be delayed and poorly developed (Baron-Cohen & Wheelwright, 2004; Rajendran & Mitchell). The TOM hypothesis has been the most heavily researched theory and remains the most influential theory within the field of autism for the time being (Smith, 2009).

From a rehabilitation perspective, it is important to consider the clinical implications and applications of these theories. As noted by Verhoeff (2013), the primary framing of autism today is as a deficit in social cognition and social instinct. Clinically, this framing has been applied as a social interpretation of observable autistic behaviours (Donnellan, Hill, & Leary, 2013; Robledo, Donnellan, & Strandt-Conroy, 2012). For instance, the DSM 5 guidelines link observable autism behaviours (such as poor eye contact, atypical speech, unusual movements) to decreased interest in others, poor understanding of social conventions and limited recognition of emotions (Carpenter, 2013).

### 1.2.1.5 Evidence used in current framing of autism

Current framing of autism has been built upon decades of research, and while dominant framings and theories have changed over time, one element has remained constant throughout the history of autism science and research. Autism science and research has consistently maintained a focus on biomedical concerns, especially those pertaining to potential causes and cures, through the pursuit of basic science (Pellicano, Dinsmore, & Charman, 2014a&b; Verhoeff, 2015). Investigating the neurobiological basis of autism has been pursued to the exclusion of research that explores the experience of autism (Amaral, 2011; Pellicano et al., 2014 a&b; Verhoeff, 2015). Often, when research has been conducted to understand the “inner workings” of the autistic mind, it has taken the form of observational research, rather than asking autistic people to
speak or type about such things (Bolte et al., 2018; Pellicano et al., 2014a; Shattuck, Lau, Anderson, & Kuo, 2018; Szatmari, 2018).

The paucity of research exploring experiences of autistic people reflects, in part, positivist traditions within healthcare research, which have historically placed priority on biomedical phenomena (Eakin & Mykhalovskiy, 2003). It also reflects a long-standing perception that the insights of autistic people are unattainable, since autistic people have challenges with communication (APA, 2013; Tager Flusberg & Kasari, 2013; Tager Flusberg et al., 2017). Early attempts at conducting interviews with autistic participants were met with challenges such as distress for participants, and difficulty accessing clear recall and answers to open ended questions (Preece & Jordan, 2010). With the growth of the neurodiversity movement, and advances in technology, researchers are beginning to find innovative ways to examine autism-insider perspectives (for examples see Danker, Strnadova, & Cumming, 2017; Satchwell & Davidge, 2018; Tager-Flusberg et al., 2017). However, this type of research remains scant (Pellicano et al., 2014a&b; Verhoeff, 2015)

1.2.2 New framing for more complete understanding

In rehabilitation and other health disciplines, there is a growing acceptance that services and their associated outcomes are improved when the evidence that informs them goes beyond biology to include the preferences and perspectives of consumers (Davies & Gray, 2017; Krummholz, 2008; Whalley Hammell, 2013 & 2015). The involvement of clients as informants and collaborators for research, policy and service design affords practical, ethical and financial benefits that are well known (Tait & Lester, 2005). Expanding knowledge of a condition to include insider perspectives leverages the experiential expertise of insiders, to improve services and outcomes, promote innovation in treatment and can ultimately promote social inclusion (Tait & Lester, 2005). Such benefits have been seen in the mental health sector, where the involvement of consumer perspective has helped to revolutionize care and optimize outcomes (Boydell, Gladstone, & Crawford, 2002; Davidson, 2016; Smart, Nalder, Rigby, & King, 2018).

1.3 Statement of Research Problem

Through review of the literature, it becomes apparent that the current framing of autism is limited in its comprehensiveness. Since autism framing has been built without the perspectives of
insiders (Amaral, 2011), and since insider perspectives are known to make framing more effective (Tait & Lester, 2005), it follows that autism framing requires broadening to include perspectives of autistic people. The literature shows a clear need for research that examines the perspectives of autistic people, to build deeper understanding and broaden and refine the way autism is framed.
Chapter 2
Research Context, Methodology and Methods

This chapter provides an overview of the research context, the methodological approach and the specific methods employed over the three studies presented in this dissertation. In this chapter, I begin with a discussion of the aims and objectives of the research. I then discuss research context and researcher positionality. I follow this with a discussion of the research paradigm and the methodological approach with an explanation of how this approach fits the intentions and execution of this body of work. Next, I cover a high-level overview of the methods used for data generation and analysis within the three studies, as well as steps taken to ensure scientific rigour. Finally, I discuss relevant ethical issues.

2.1 Research Aims and Purposes

As discussed in Chapter 1, the literature suggests that the limited scope in autism research, which has essentially covered a basic science examination of biomedical topics, has led to a significant gap in our understanding of autism, especially in terms of understanding observable autistic behaviours (Amaral, 2011; Pellicano et al., 2014a&b; Verhoeff, 2015). This dissertation research aims to address this gap by exploring the ways autistic people understand autism and its core behaviours. By doing this, this research has sought to uncover new concepts and new directions for future research. This research is intended to ultimately make some early contributions to insider-informed-evidence-based practice in the field of autism.

2.2 Research Context

In autism research, contextual factors are especially pertinent, since the field of autism science has more context-bound variance in perspective than most other disciplines (Bagatell, 2010; Dawson & Bernier, 2013; Verhoeff, 2013). This is because dominant autism framing has changed over time and because clinician or researcher framing of autism is strongly shaped by discipline (Bagatell, 2010; Dawson & Bernier, 2013; Donnellan et al., 2013; Verhoeff). Autism framing also varies outside of clinical and academic contexts. For instance, mass media, parent
advocacy groups and autism self-advocacy groups have all been seen to frame autism differently (Parsloe & Holton, 2018; Pellicano et al., 2014a&b), making context particularly relevant.

The research within this thesis was conducted as part of the requirements of a PhD in rehabilitation science at the University of Toronto. The advisory committee was an assemblage of very experienced researchers, three with backgrounds in occupational therapy and one with a background in nursing. These contextual elements, as well as the positionality of the primary researcher (discussed in the next section) have bearing on the research, since each investigator approaches research with pre-shaped views on autism. Additionally, working within the Rehabilitation Sciences Institute creates a research-culture and ethos toward autism that may be different from other departments such as sociology or medicine.

The studies in this thesis use extant texts: memoirs and blogs. When working with these texts, researchers must give added consideration to the context of the data (Ralph, Birks, & Chapman, 2014). These authors (2014) recommend a process of contextual positioning in which the researchers ask context-specific questions of the data to develop some contextual awareness prior to analysis (Ralph et al.). One such question is, “Who benefits from the production of this writing?” It is worth noting that the three published memoirs used in Study #1 had been produced for sale and two of the blogs sampled in Study #2 and Study #3 had related books for sale. Additionally, one blog in Study #2 and Study #3 had a charitable foundation attached to the blogsite. Contextual positioning also asks, “what is the stated purpose?” (Ralph et al.). The three published memoirs used in Study #1 and most of the blogs used in Study #2 and Study #3 gave a stated purpose of educating others about autism.

Temporal context is another important consideration (Ralph et al., 2014). The publication dates of the memoirs included in the first study spanned the years 2007 to 2012. The temporal context of the blogs spanned roughly 2013-2018, however temporal context was sometimes obscured as some blog posts did not include dates.

Geographical context should also be considered. In Study #1, the memoirs were sourced from within Canada but were written by youths from Canada, the US (though he was born in India) and Japan. The second and third studies (which used a shared dataset) used blogs written from Canada, the U.S., the U.K., Australia and the Netherlands, as well as some blogs that did not specify their geographic location.
2.3 Reflecting on My Positionality

Reflexivity is an important part of rigorous qualitative research. Reflexivity refers to sensitivity to and awareness of how the researcher and the research process have shaped the data generation, the analysis, the findings and the representation (Mays & Pope, 2000). I have been engaged in critical self-reflection throughout, as suggested by Finlay (2006), to realize how my background, social status, assumptions, clinical experience, as well as personal and intellectual biases have impacted the research in this thesis.

According to Mays and Pope (2000), there are many elements to the position from which one can approach research, such as age, sex, social class, and professional status. In my case, I believe the most salient component of my positionality is my status as an occupational therapist (OT) who has been practicing for seventeen years, primarily with autistic children. My work as an OT has instilled in me personal and intellectual assumptions, such as the assumption that participation (functioning at the societal level) is critical to quality of life (Polatajko et al., 2007). My work as an OT also involved immersion in the academic literature and I initially approached this research with an understanding of autism that was consistent with the dominant framing. As an occupational therapist, I have always been concerned with evidence-based practice, which has shaped my understanding of what research is for and what constitutes “good” research (namely research that improves intervention by making it more effective and/or more ethical and compassionate).

A critical part of reflexivity is evaluating the “distance” the researcher has from the phenomena of interest (Mays & Pope, 2000). In my case, it is important to note that I do not identify as having autism, nor do I have a loved one or family member who identifies this way. I do hold some proximity to autism however, in that children with autism have been a major part of my practice for the last fifteen years. Over those years, I have generated many ideas and assumptions about autism and have developed personal attachments to a number of autistic people. Knowing many autistic children over the years has developed in me a feeling of investment in improving interventions and participation opportunities for these children and for their future adult selves. This has influenced me throughout the research process. It has heightened my emotional responses to the data; it colours my reporting and impacts the elements of the phenomena that I choose to focus on most closely. For instance, I have been keen to understand what autistic
people want from interventions. Also, I expect emotion comes through in some of my writing, since this research process has been emotionally engaging and sometimes challenging (for instance when I was forced to consider that some of my clinical practices may be misinformed).

2.4 Research Paradigm

The approaches applied in this research reside within a constructivist paradigm of enquiry. I approach the research with an understanding that I am not an objective observer who is separate from the research, its process or its products (Annells, 1996). Though the data were not co-constructed in the more traditional sense (I used non-elicited, extant texts), I recognize that I am part of the research, beginning with the formulation of the research question (which reflects my worldview including what is worth knowing and what can be known) (Annells). I acknowledge that the instant I gaze upon text and consider it “data”, I am transforming that text and engaging in a “constructive act”, which continues throughout the research process (Annells; Charmaz, 2006). For these reasons, I understand that while I worked to get as close as I can to the inside of the experience of the informants in this research, I cannot understand it or present it perfectly – it has been changed by me and the same data in the hands of another researcher (and advisory committee) would be transformed and interpreted in ways that may have similarities, but would not be the same.

In approaching this research, I take an ontological position of relativism. I consider reality to be dynamic and context-specific. I see that social and natural worlds have differing realities; however, I believe that both forms of reality are understandable, albeit in approximate and imperfect ways (Annells, 1996). In this research, I pursue deeper understanding of the phenomenon that is autism and I present an interpretation of insider perspectives that I believe can build toward a shared understanding across people who do and do not have autism (an admittedly approximate, imperfect and context-bound understanding). This means that I cannot claim to produce research that offers a singular or perfect reality.

Epistemology is concerned with how knowledge can be created, developed and communicated (Denzin & Lincoln, 2011). Epistemology both guides and is reflected in the ways a researcher goes about obtaining valid knowledge. I view individuals’ knowledge to be both subjective and transactional (Bradshaw et al., 2017). I believe that autism knowledge is most valid if it is built
through multiple types of knowledge, including experiential knowledge. I understand that the knowledge generated in this research is imperfect, fluid and context-bound.

2.5 Methodology

A methodology is the rationale for the research approach, and the lens through which the analysis is conducted (Howell, 2013). Methodological assumptions determine how researchers go about finding what they believe can be known, while they work to achieve an optimal fit respective to the phenomena of interest (Denzin & Lincoln, 2011). The methodological approach employed in the research within this thesis is qualitative description (also known as a qualitative descriptive approach).

According to Bradshaw, Atkinson and Doody (2017), “A qualitative description design is particularly relevant where information is required directly from those experiencing the phenomenon under investigation.” (p.1). This fits squarely with the objectives of the research within this thesis, which aims to build understanding of autism by bringing to light the perspectives of people who have it, in the context of a dominant autism frame that has been constructed by people who do not have it (Amaral, 2011; Pellicano et al., 2014 a&b; Verhoeff, 2015).

Qualitative description research seeks to understand a phenomenon based on the perspectives and worldviews of the people involved (Bradshaw et al., 2017). What sets qualitative description research apart from other qualitative research approaches is its aim to develop an understanding of a phenomenon by adhering as closely as possible to the meanings participants ascribe to relevant experiences of it (Bradshaw et al.; Hickey & Kipping, 1996). This means that the researcher is more concerned with presenting a rich description of the participant accounts than with presenting a highly abstract interpretation of participant accounts (Bradshaw et al.).

Within a qualitative description approach, it is understood that a level of interpretation is always present when a researcher engages with data, and that the research output is not untransformed or atheoretical (Bradshaw et al., 2017; Sandelowski, 2000). Still, in qualitative description, the emphasis is placed first on a literal description and then on the understanding of phenomena through analysis and interpretation of the interpretation that the informants attach to events and experiences. The important characteristic here is the degree to which the data have been
transformed (Sandelowski, 2000). In the case of the research in this thesis, I have transformed the data to a lesser degree than one might see in different qualitative methodologies. Additionally, in my interpretation of the data, I adhere to the interpretations that I believe the informants themselves have ascribed to the events. For instance, informants in this research describe “meltdowns” as events that entail actions beyond their own control. In my interpretation, I link this description to literature, and to other patterns I see within the dataset. And so, I have interpreted the data, but at a more proximal level than if I were to have “read between the lines” and presented “meltdowns” as something abstracted from the informants’ literal description. For example, if I were to identify “meltdowns” as a subconscious or subverted expression of anger towards an ableist society.

Linking this methodological approach again to our research objectives, qualitative description is a suitable approach because the work in this thesis endeavours to build understanding of autism by leveraging autistic peoples’ understanding of autism and is therefore suitably done by leaving the expertise of the informants intact.

2.6 Methods

A wide array of methods can be used within qualitative description research, provided they are consistent with the research question and the purpose of the research, and contribute to the rigour of the work (Bradshaw et al., 2017). Qualitative description is a naturalistic approach that requires a flexible plan of inquiry, as it must be responsive to real world contexts and sometimes, surprising findings (Sandelowski, 2000). The latter was true throughout the three studies of this research, which indeed generated surprising findings and required flexible plans of inquiry.

2.6.1 Data generation

2.6.1.1 Data sources

Qualitative exploration of the experiences of autistic people comes with challenges based on the communication difficulties experienced by the population (Anagnostou et al., 2014; Preece & Jordan, 2010). This indicated the need to be innovative in sourcing data. For Study #1, I used published memoirs written by autistic people as the data source. I found this suitable because memoirs can to bring to light previously unseen elements of people’s daily lives and highlight
matters of importance to the people who write them rather than what has been identified as important by researchers (Power et al., 2012).

Building on Study #1, my aim was to further explore autism insider perspectives, including perspectives on specific phenomena of interest. I approached data generation for Studies #2 and #3 (which both used a single dataset) with the concern that the phenomena of interest may be experienced only rarely and therefore difficult to find discussions of. This motivated me to “cast a wide net” to find discussions of the phenomena of interest. Increasingly, autistic people are finding ways to successfully communicate and interact online (Brownlow & O’Dell, 2006), including blogging. Blogs have been shown to be excellent sources for qualitative data (Hookway, 2008) as they combine the contextualization and rich description of diaries with the far reach of the internet. Accordingly, I chose blogs as the data source for the second and third studies as this facilitated sampling across geographic borders and time (since blogs are often archived for many years) while gaining rich data (Hookway; Salmons, 2012). To generate data from blogs, I used “blog trawling” a system of searching extant blog posts for content discussing the phenomena of interest (Hookway).

2.6.1.2 Data selection

In Study #1, initial data selection required that the memoirs be available in English and written from a first-person perspective by an autistic person. There was a multistep selection process, which began with open reads of the data corpus (five memoirs). During the open reads, I began to take more specific interest in experiences of embodiment and being misunderstood. There were three memoirs that discussed these concepts, while two memoirs did not. Based on review with the research team, I decided to focus more closely on the phenomena of embodiment and being misunderstood and began analysis on the dataset of three memoirs. Upon further analysis, the research team and I were eventually satisfied that the three memoirs provided sufficient rich description to meet the objectives of the study and no further data was generated (Welch et al., 2018). For a more complete summary, see Chapter 3.

In the second and third studies, I set broad initial inclusion criteria. Blogs were included for data extraction if they were written in English, by people of any culture, gender, geographic location or level of severity on the autism spectrum. I did not exclude any blogs based on when they were written. I excluded blogs written by parents, scholars or professionals if they did not identify as
autistic themselves. Text was extracted from blogs into the dataset if it related to concepts of embodiment or being misunderstood (building from the first study) or if it offered explanations for autistic behaviours and characteristics. For a more complete summary, see Chapters 4 and 5.

2.6.1.3 Data analysis

The analytic lens throughout the three research studies within this dissertation was shaped by our application of a qualitative description approach (see methodology section for a description of this and its implication for data analysis). Analytic methods differed somewhat between the studies. Study #1 used a completely inductive approach to thematic analysis. All of the codes and themes that were developed throughout the analysis came from the dataset itself, with no a priori themes or specific priorities of interest. In Study #2, I conducted a directed content analysis (Hickey & Kipping, 1996), applying a pre-designed codebook consisting of codes that were generated in the first study (Appendix B: Initial codebook Study #2). In the third study I used the same dataset from Study #2, this time engaging in inductive thematic analysis, drawing on data that did not fit with the a priori themes identified in the earlier studies, but had relevance to understanding of autism.

For all three studies, analytic methods followed a structure proposed by Braun and Clarke (2006): an iterative process of coding, collating, mapping, reviewing, creating clear themes, and then reporting using compelling extracts. I found the Braun and Clarke structure to be suitable to the qualitative description approach as it results in proximal levels of abstraction. Analytic memoing was used throughout the entire research process to keep track of researcher responses, ideas and design decisions. See Chapters 3, 4 and 5 for more complete descriptions.

2.7 Quality and Rigour

Throughout the research in this thesis, I sought to ensure criteria of rigour outlined by Charmaz (2006): credibility, originality, resonance and usefulness. I sought credibility by: 1) achieving intimate familiarity with the topic, 2) gathering rich data (sufficient in range, volume and depth to merit the study’s claims), 3) creating strong and logical links between the data gathered and the argument and analysis, and 4) providing enough evidence for the reader to form an independent assessment of the studies’ claims.
I sought originality by: 1) creating fresh themes and concepts that offer new insight, 2) providing an analysis that offers a new conceptual rendering of the data, 3) creating work that has practical significance, 4) constructing new concepts that challenge, extend or refine current ideas, concepts and practices.

I strove for resonance by: 1) generating themes and concepts that portray the fullness of the studied experience, 2) drawing links between larger collectives / institutions and individual lives when indicated by the data, 3) presenting concepts that make sense to people who have autism, 4) giving an analysis that offers deeper insights about the worlds of people who have autism.

I pursued usefulness by: 1) creating an analysis that offers interpretations that people can use in their everyday worlds, 2) creating work that contributes new knowledge.

Bradshaw and colleagues (2017) propose indications of rigour specific to a descriptive qualitative approach. They emphasize the importance of ensuring rigour from the outset of research, rather than as a sort of “safety check” later in the process. In this research, I worked to ensure rigour throughout the entire research process. Accordingly, this research involved detailed record keeping of all elements of the research process including notes from supervisory and advisory committee meetings, reflexive memoing during and between immersions in the data, detailed code book development (Appendix C: Final codebook), descriptive documentation chart (Appendix A: Descriptive documentation chart), and a blog trawling diary.

Bradshaw and colleagues (2017) identify prolonged engagement (with participants and with data) as an indicator of rigour within qualitative description. This research spans over four years, and since extant texts comprised the dataset, very little of the four years was spent on recruitment or data generation, rather it was spent immersed in the data: reading, re-reading, coding, collating, etc.

Finally, an important element of rigour that is specific to a qualitative descriptive approach is the use of direct quotations from informants (Bradshaw et al., 2017). All reporting of results within this thesis use direct verbatim quotations. I strove for detailed and transparent reporting of the research process, including any changes in the direction of the research, as deemed important by Bradshaw and colleagues. The detailed reporting is meant to be sufficient for recreation to occur,
though it is possible that some blogs will be taken down in future and, of course, exact replication would not be possible with a different research team.

2.8 Ethical Considerations

Embarking on this research, I was committed to producing work that was scientifically valuable and clinically useful while adhering to my commitment as an OT to “do no harm” (AOTA, 1984). As the work progressed, I found that the ethical considerations relevant to this research became increasingly complex. In this section, I discuss the most salient ethical considerations in the context of these studies and the procedures ultimately implemented.

To ‘do no harm’, Eynon, Fry and Schroeder (2008) propose three concepts at the core of human subject research: confidentiality, anonymity, and informed consent (see also Lawson, 2004; Sveningsson, 2004). Here, I shall discuss these core tenets as I applied them in my thesis research.

Informed consent is important in human subject research (Eynon et al., 2008); however, it has long been accepted that certain kinds of research can ethically proceed without informed consent, such as observational research in public places, or textual analysis of documents that are fully and clearly in the public domain (Willis, 2018). In this thesis two types of information were accessed - memoirs and blogs. The assignation of “public” is relatively easy to ascertain in the case of published memoirs (data source for Study #1), but harder to determine within an online context (Studies #2 & 3 used online sources). According to Willis, different online forums have different levels of “publicness” and that the level of “publicness” or privacy perceived by the online user can be measured by two factors: 1) how technically accessible the platform is and, and 2) how the forum users intend the information to be used. For example, a chat room with a stated purpose of providing mutual support to people with a certain condition would be considered to have a level of privacy, especially if it has restricted technical access such as a password requirement.

For this research, I have only included publicly available published memoirs and blogs that would be considered public by both measures specified by Willis (2018). Blogs were only included if they did not require passwords and did not have “members only” or “friends only” statements on the homepage. Additionally, I found that most blogs had a stated purpose which
explicitly stated that the blog is written to educate other people about autism, to dispel misinformation about autism, to reduce the stigma of autism, or to improve the lives of other people with autism. This suggested that these blogs are public based on Willis’s second measure of “how the authors intend the information to be used”. I applied for, and received, ethical approval from the Health Sciences Research Ethics Board at the University of Toronto to proceed without informed consent from the bloggers, based on this rationale. Additionally, I considered the fact that a requirement of informed consent would greatly reduce the quantity and quality of the dataset (because many blogs are archived or do not leave ways to contact the author) and ultimately reduce the scientific value of this study.

The decision to view blogs as public material has important consequences with respect to matters of confidentiality, anonymity, and citation (Roberts & Sipes, 2018). This designation frames the bloggers as “authors” rather than “participants” (Roberts & Sipes), which evokes copyright considerations, requiring that I properly cite sources of the texts. The requirement to cite sources removes the option of anonymizing the data to protect confidentiality of informants. The dilemma of source-citing may even be moot since it is sometimes possible to trace quoted material to its online source by cutting and pasting into a search engine (Willis, 2018). One solution available to researchers is to paraphrase informants’ accounts, however this is not a valid option within this study because verbatim quotes are an important element of rigour within a qualitative description approach (Bradshaw et al., 2017). A final and extremely important consideration in this issue, is the expressed wishes of the bloggers. Several bloggers explicitly stated that they are open to having elements of their writing featured in other blogs and research, writing, but that they wish to get proper credit:

“If you use ideas from this in research or elsewhere, please give me credit.
Autistic people are often not given credit for our ideas when people mine them for research, so this is more important than usual.” (Baggs, 2016)

This thesis cites blog text according to APA referencing guidelines. This means that the author’s name is used if possible. Some bloggers choose to protect their identity by publishing under pseudonyms or do not provide a name. In these cases, the pseudonym or the blog title is used in place of author name.
While analysis of memoirs and blogs are a “non-invasive” way to conduct research, there are still risks of harm (Zimmer, 2010). Memoirists and bloggers who learn that their writing has been used for research purposes could feel “othered” (Zimmer) or could feel misrepresented, if they do not agree with the way their writings have been interpreted and presented (Zimmer). I have tried to mitigate these risks by using a descriptive qualitative approach which limits the level of researcher abstraction and strives to keep the “participants” meaning intact with their words (Bradshaw et al., 2017). Also, I have approached the data with respect and sensitivity and have always been mindful of how my researcher intentions align with stated priorities of the bloggers. Like the bloggers in this thesis research, the informants in a study by Pellicano and colleagues (2014a), expressed desire for more research that dispels myths of autism, that highlights perspectives of people who have autism, and that has the potential to improve treatment for people who live with autism. I feel that on balance, the risks of harm and the potential for benefit for autistic people support this study and its methods.

Study #1 was completed without REB review, based on the understanding that it “…uses exclusively publicly available information that may contain identifiable information, and for which there is no reasonable expectation of privacy.” (University of Toronto, Research and Innovation, 2018).

Studies #2 and #3 received ethical approval from the Health Sciences Research Ethics Board at the University of Toronto.
Chapter 3
Autism Inside Out: Lessons from the memoirs of three minimally verbal youths

This chapter has been published, with slight changes (Vancouver-style formatting) in the Journal of Disability and Rehabilitation. Permission to reproduce the article for this dissertation was granted by the permissions administrator at Taylor & Francis Group.

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3 Autism Inside Out: Lessons from the memoirs of three minimally verbal youths

3.1 Abstract

**Background:** To date, research exploring experiences and perspectives of people who have severe autism and are minimally verbal, has been sparse. **Objectives:** To build new understanding based on insider perspectives of people who have severe autism and are minimally verbal. We took interest in how these perspectives support, challenge, or augment current depictions of autism in academic literature. **Method:** Adopting a descriptive qualitative approach, three memoirs written by youths who have severe autism and are minimally verbal were examined using inductive thematic analysis. Analytic methods followed a recursive process of coding, collating, mapping, reviewing, creating clear themes, and then reporting using compelling extracts. **Results:** Analysis generated an over-arching theme regarding the youths’ concern that the way they are perceived from the outside does not match the people they are on the inside. In explaining this mismatch, the youths identify differences in the way their brains work, as well as difficulty controlling their bodies. **Conclusions:** These youths emphasize concepts of embodiment and physical control as central to their experiences of autism. Findings highlight the need for research exploring insider perspective and the development of innovative methods to gain insight into the understanding and interests of people who are minimally verbal.

3.2 Introduction

In this study, we conducted an inductive thematic analysis of three memoirs written by youths who have severe autism and are minimally verbal. We pursued the question “What insider understanding of autism is presented in these published memoirs?” We discuss our findings in the context of relevant literature as well as possible implications for research and practice.

3.3 Background

Autism Spectrum Disorder (autism/ASD) is a neurodevelopmental condition characterized by differences in social communication and atypical, restrictive, or repetitive behavior (APA, 2013). It is linked to a broad spectrum of daily functioning and verbal ability (Anagnostou et al., 2014;
Munson et al., 2008). This paper is focused on individuals on the spectrum who have severe difficulties with verbal speech whom we will refer to as “minimally verbal” as suggested by Tager-Flusberg and colleagues (Tager-Flusberg et al., 2017; Tager-Flusberg & Kasari, 2013). These individuals have verbal communication skills that range from a restriction to non-speech sounds, to ability to use a few words or fixed phrases (which may or may not be echoed or scripted). Within the population of people who have autism, it is estimated that about thirty percent have verbal abilities within the minimally verbal range (Tager-Flusberg & Kasari, 2013).

Autism is intensely researched around the world (Tomlinson et al., 2014) with hundreds of millions of dollars going to autism research in North America alone (Canadian Institute of Health Research, 2017; Pellicano et al., 2014a). Most research on autism has taken the form of “basic research” addressing biomedical topics with little exploration of the first-hand experiences of these individuals (Pellicano et al., 2014a&b; Zwicker & Herbert Emery, 2014). Qualitative work engaging people who have autism on the severe end of the spectrum and are minimally verbal is particularly absent from the literature (Tager-Flusberg & Kasari, 2013).

Autism researchers face legitimate challenges to pursuing explorations of first-hand perspectives and experiences of participants since difficulty with communication is a diagnostic feature of autism (APA, 2013). Where it has been attempted, researchers have reported participants becoming distressed while being interviewed as well as having difficulty remembering past events, discussing their emotions, and answering open-ended questions (Preece & Jordan, 2010). Conducting such research with people who are on the severe end of the spectrum and are minimally verbal has been especially challenging, however, it is becoming more feasible as more minimally verbal people develop effective communication systems through use of sign language, Picture Exchange Communication System (PECS), Voice Output Communication Aids (VOCA), or writing/printing (Tager-Flusberg & Kasari, 2013).

Despite its challenges, exploration of the perspectives and experiences of people who have severe autism and are minimally verbal is critical and should be pursued. It is generally known that practice in education, applied behavior analysis, occupational therapy, and other therapeutic fields should be based on evidence that includes perspectives of the people whom that practice aims to serve (Boydell et al, 2002; Whalley Hammell, 2013 & 2015). Further, exposure to insider perspectives can stimulate critical thinking in professionals, which in turn can lower risk
of acting on faulty assumptions (Whalley Hammell, 2015). These are important advancements still needed in the autism scholarly literature, so innovative methods must be employed to pursue these important, yet hard to reach perspectives. This paper uses one such innovation – the examination of memoirs written by individuals who self-identify as being autistic and minimally verbal. Memoirs published by people who identify as having autism have become increasingly available in recent years.

Memoirs are generally considered an excellent source of rich data, which can be gathered in a low-cost and time effective way (Power et al., 2012). Power and colleagues point out that memoirs have the potential to improve understanding by making visible, previously unseen elements of people’s daily lives (2012). They also point out that memoirs can make an important contribution to new knowledge by highlighting things of importance to those who write them, rather than what has been assigned importance by researchers and professionals (Power et al., 2012).

In consideration of the identified gap in the literature and the availability and suitability of memoirs, we embarked on this study. Since our desire was to ultimately focus on items identified as important by the memoirists themselves, we began the study with an extremely broad objective: to build understanding of autism based on insider perspective.

3.4 Methods

A descriptive qualitative approach was used to gain understanding of experiences and perspectives of some people who have autism. As Sandelowski (2000) explains, descriptive qualitative research provides an intensive and immersive look at events or activities in everyday terms. In this approach, the aim is to provide a careful account of events or experiences, with minimal theorizing (Sandelowski).

3.4.1 Study context

This study was conducted as the first phase of a doctoral research project designed to explore first-hand experiences of autism. Since I (primary author – Welch) carried out all initial reads and data coding, my positionality is of particular importance. I am an occupational therapist who had been practicing for 15 years at the time of the study, primarily with children who have autism and their families. As such, I had developed a perspective on these children and their
behaviors. I also maintained immersion in the autism literature over this time, which offered certain perspectives. It was a persistent gap in my understanding of autism, despite ongoing practice and engagement with the literature that prompted my pursuit of doctoral studies.

Interest in this study began when I came across online video of an interview with Carly Fleischman, a young woman who has severe autism and is minimally verbal. Watching this video, I was struck by the juxtaposition of Carly’s level of verbal ability (she does not verbally produce words) and observable behaviors (rocking, humming, hitting the couch with her hand) over the typed words of her interview, which were eloquent, socially insightful and in some ways contrary to my understanding of autism at the time. I instantly felt tension between my curiosity to know more and my fear of discovering that my understanding (and therefore my practice) pertaining to autism up to this point were more flawed than I had realized. This led to further reflection and the abandonment of previous research plans (which were more quantitative in nature) in favor of exploring the perspectives of people with autism themselves.

The approach to analysis was also shaped by these contextual elements. My experience as a clinician and my long-term immersion in autism literature informed my starting position in this research. For instance, while looking for patterns within the data, I had a heightened awareness of when the perspectives in the memoirs diverged from my own understanding of autism. Also, my clinical background drew my attention to descriptions that might give insight related to intervention. Despite starting with a very broad research objective, as analysis progressed, I became increasingly focused on content relating to the internal or embodied experiences of autism as well as the ways in which the memoir authors described how they believed themselves to be perceived by others. The memoirs that were included in this study are rich with opportunity for analysis: more than can be covered in one study, such that some interesting patterns noted (e.g., all three autobiographers discussed “melt downs”) are not included in the data presented here. This directly reflects the positionality of this research team, since another team may have given primacy to this or other patterns in this data.

3.4.2 Refining the research question

In keeping with the approach that guided this study, refinement of the research question was an iterative and reflexive process. We initially interrogated the data with the very broad and generative question “What new understanding of autism is presented in these published
memoirs?” As I (primary author – Welch) was conducting preliminary open readings of the memoirs and engaging in reflexive memo writing, I noticed patterns within some of the writings that were particularly compelling and relevant to the pursuit of new understanding. It so happened that these patterns were seen specifically in the memoirs that were written by minimally verbal youths. In response to the development of this more focused interest, the research question was narrowed to “What understanding of autism is presented in the published memoirs of these minimally verbal youths?”

3.4.3 Data sources and selection

Initial data selection was based on broad criteria and required only that the memoirs be available in English and written from a first-person perspective by a person who self-identifies as having a diagnosis on the autism spectrum. Five published memoirs, written by individuals who identify as having a diagnosis on the autism spectrum, were initially obtained, with potential to narrow down further, or engage in further data generation, as recommended by Braun and Clarke (2006). Two memoirs written by adults who have high verbal skills (Elder Robison, 2007; Grandin, 1996) were among the initial five as this fit within the original, more broad research objective, but were not selected for the final data set as they did not discuss what developed as our phenomena of interest over the first open reads of the five memoirs.

From among the initial five, three were chosen for inclusion in this study. The selection process was multistep. First, open readings with reflexive memo writing were conducted by me (primary author – Welch) on all five books. Reflexive memo writing is a continuous component of the analytic process that documents the investigators’ thoughts, questions, and responses that form while engaging with the data (Charmaz, 2006). Books 1, 2, and 3 (listed below) seemed particularly compelling relative to our research interest of building new understanding of autism based on insider perspective. The books that we did not select (Elder Robison, 2007; Grandin, 1996) were written in a highly narrative style: telling their life stories in ways that made sense chronologically. Their accounts had plots and characters and contained rich descriptions of situations they encountered, how they understood them and the emotional impacts of their experiences. In contrast, the books written by Naoki Higashida, Tito Mukhopadhyay, and Carly Fleischman, mentioned important people in their lives but had a much stronger focus on experiences they encountered regularly, with detailed description of episodic experiences. These
three writers described experiences which were compelling and resonated for me (primary author – Welch) in the context of my clinical experience with individuals with autism. Carly, Tito, and Naoki also discussed their experiences and understandings of autism in direct comparison to dominant perceptions among the general public. These three authors all wrote their memoirs while in their teens, they describe their autism as severe and they self-identify as minimally verbal. So, while the original research question pertained more broadly to people with autism, it was at this point refined to focus on youths who identify as minimally verbal.

At this point, two memoirs were excluded (Elder Robison, 2007; Grandin, 1996), with the continued potential for ongoing inclusion and exclusion of data as recommended by Braun and Clarke (2006). After additional reads, the rich descriptions found in memoirs one, two, and three listed below) convinced us that these three books could sufficiently form the data set, in keeping with Braun and Clarke (2006), to meet the objectives for this research and no additional books were sought out.

3.4.4 Memoirs selected

1. Carly’s voice: Breaking through autism (2012). Carly and her father, Arthur Fleischman. (written at age 16). Carly grew up and lives in Canada. She was diagnosed with autism in early childhood. She began typing to communicate when she was 11 years old. While this memoir contains writings by Carly’s father Arthur Fleischmann, only writings by Carly were considered [and later extracted] for the data set (Fleischmann & Fleischmann, 2012).


3. The Reason I Jump (2007, translated 2013) – Naoki Higashida (written at age 13). Naoki grew up and lives in Japan. He was diagnosed with autism at age five. He can say some words but self-identifies as non-verbal because he is not able to carry on reciprocal verbal conversations. He uses typing as well as a homemade symbol board for communication (Higashida, 2007).
3.5 Authenticity of Memoirs

Authenticity of authorship is of particular interest when authors self-identify as being minimally verbal, especially in the field of autism where some individuals use “facilitated communication”, a technique which involves typing with physical guidance from another person (Saloviiita, Leppanen, & Ojalammi, 2014). The technique has been debated in the academic literature and is considered non-evidence based (Trembath et al., 2015). None of the authors of the books that formed the data corpus for this study used facilitated communication in the writing of his or her book. Indeed, the youths explicitly state that their written communication is not facilitated by someone else; Carly typed herself, Tito wrote and typed himself, and Naoki used a combination of typing and pointing to a homemade “symbol board” while someone else typed.

A consideration in reviewing these books was the seemingly uncommon presentation of Carly, Tito, and Naoki writing and typing so eloquently in the context of their inability to communicate verbally. While there is an assumption that people who do not acquire verbal speech have low IQs, and do not have rich and eloquent internal dialogs, the fallibility of this assumption has been demonstrated in other work (Munson et al., 2008; Falkman, Dahlgren Sandberg, & Hjelmquist, 2002; Tager-Flusberg & Kasari, 2013). Further, it is worth considering that IQ is generally assessed through measures that rely on overt verbal or motoric responses (as opposed to directly reflecting thought processes).

3.6 Data Analysis

The analytic process followed a structure put forward by Braun and Clarke (2006): a recursive process of coding, collating, mapping, reviewing, creating clear themes, and then reporting using compelling extracts. This analytic approach was determined to be a good fit based on two characteristics described by Braun and Clarke (2006): (1) it results in fairly proximal levels of abstraction – we sought to stick close to the authors’ descriptions, (2) it is theoretically flexible, which makes it easy to fit within a larger body of work. The latter was an important element for us to consider as this study is meant to lay groundwork for future research exploring insider perspectives on autism. The process was conducted in a recursive and iterative manner, with analytic memo writing throughout as recommended by Charmaz (2006).
With the three memoirs selected as the data set [which Braun and Clarke (2006) would describe as all the data from the data corpus that are being used for a specific analysis], they were initially subjected to several open reads, with reflexive memo writing. Memos included page references, identifying sections of text that the PA found powerful, compelling, curious, or gave episodic descriptions of daily experiences.

Additional considerations outlined by Charmaz (2006) were also incorporated: (1) the data were extracted verbatim, and then were checked against the books for accuracy. (2) Each data item was given equal attention in the coding process. (3) Themes were not generated from a few vivid examples (an anecdotal approach), rather, the coding process was thorough, inclusive, and comprehensive. (4) All relevant extracts for each theme were collated. (5) Themes were checked against each other and back to the original dataset.

3.7 Ethical Considerations

Though all data were collected from public sources, issues of privacy, anonymity, confidentiality, consent, and potential harm or intrusion must still be considered (Zimmer, 2010). It would be impossible to strip identifiers from these data; thus it has not been used anonymously. While all three authors wrote their accounts for public reading, and all three explicitly expressed desire to promote improved understanding of autism, we realize that is not the same as offering their narratives up to be analyzed, compared to other narratives and then presented out of the initial context. With this in mind, we have made every effort to be respectful of the data and we mindfully applied Braun and Clarke’s (2006) approach to thematic analysis to produce a proximal level of abstraction and stay close to the memoirists’ original accounts.

3.8 Findings

Through thematic analysis, we developed three themes as well as one meta-theme across the memoirs that highlight experiences described by Carly, Tito, and Naoki. The first theme is named Autism Inside My Body. It relates to experiences of limited control over one’s movements (both starting and stopping). It also highlights other experiences such as feelings of detachment from the body and physical reactions to emotional experiences. The second theme we call Autism Inside My Brain. It encompasses passages in which Carly, Tito, and Naoki share their insights regarding how autism impacts components of their brain function, such as
sensory perception and memory, in comparison to how they believe these functions perform in people who do not have autism. We have named the third theme Autism from the Outside. This theme includes Naoki, Carly, and Tito’s descriptions of how having autism has disrupted their connections with other people: the way they believe they are perceived by friends, families, and professionals as well as their own emotional responses to how they believe themselves to be perceived by others. All three of these themes are encompassed by one meta-theme: My Inside and Outside Do Not Match: the overarching problem Carly, Tito, and Naoki describe, which is that what people see from the outside (people who tantrum and “stimm” and are therefore uncomprehending and childlike) do not match who they are on the inside (intelligent, insightful, socially interested youths). Figure 3-1 presents a diagram of the thematic map created during analysis.

**Figure 3-1 Thematic map**
3.8.1 Autism inside my body

In discussing their daily lives, Carly, Naoki, and Tito frequently talk about what is happening inside their bodies. Their accounts often pair emotional experiences with physical ones. They discuss their own behavior in terms of “what their bodies do” and describe having little control over this. They discuss brain–body connections that are too intense some of the time and at other times too weak or totally absent.

3.8.1.1 I can’t stop my body

The three youths describe frequent difficulty stopping their bodies from making unwanted movements. It is this difficulty that they most often link to challenges in daily functioning, problems with communication and behaviors they find embarrassing.

*It might not seem like I am at times, but I try very hard to act appropriately. It is so tough to do and people think it is easy because they don’t know what is going on in my body. They only know how easy it is for them. Even the doctors have told me that I'm being silly but they don't get it. If I could stop it I would, but it's not like turning a switch off. It does not work that way. I know what is right and wrong but it's like I have a fight with my brain over it.* – Carly, p. 233

3.8.1.2 I can’t start my body

Another tremendous source of frustration for Carly, Tito, and Naoki, is difficulty setting their bodies into motion upon demand.

*There are times when I can't act, even though I really badly want to. This is when my body is beyond my control. I don’t mean I'm ill or anything, it's as if my whole body except for my soul, feels as if it belongs to somebody else and I have zero control over it. I don't think you could ever imagine what an agonizing sensation this is.* – Naoki, p. 32

3.8.1.3 I am helpless in my body

Unsurprisingly, the repeated failures to control movement (both starting and stopping) lead to what the youths describe as feelings of helplessness as well as betrayal by their own bodies.
We don’t even have proper control over our own bodies. Both staying still and moving when we’re told to are tricky – It’s as if we are remote controlling a faulty robot. – Naoki, p. 24

Tito describes his response to an upsetting incident [he was aboard a crowded subway train that stopped and went dark] and the help he received from a support worker this way:

I felt Arnell’s (support worker) hold all around my body, protecting my limbs, lest they act unfaithful to my soul. – Tito, p. 193

You can’t always tell just by looking at people with autism, but we never really feel that our bodies are our own. They’re always acting up and going outside our control. Stuck inside them, we’re struggling so hard to make them do what we tell them. – Naoki, p. 33

3.8.1.4  Emotions feel physical

According to Carly Tito and Naoki, another part of living inside an autistic body is that feelings based on emotion often translate to intensely physical experiences of anguish or elation. In these descriptions, mind, and body seem too closely entwined.

Pain includes mental pain, which can cause intense physical experiences. A torn page in a book may cause my whole body to itch. I experience terrible anxiety, which is as intense as any pain when a schedule is disrupted. A feeling of nausea overwhelms my whole epiglottis. What do I mean by a disrupted schedule? I have a mental map of how things should happen around me. When they do not take place as expected, the anxiety is no less than any physical pain. It produces an amplified sensation throughout my gut. – Tito, p. 210

3.8.1.5  I feel detached from my body

Somewhat paradoxical to the descriptions of feeling emotions physically are descriptions in which Carly, Tito, and Naoki feel too little from their bodies. Some descriptions sound rather like they lose track of their limbs and they do not realize they are making certain movements (like hand flapping) or sounds (like screaming).
In gym class, my teacher tells me to do things like “Stretch your arms!” and “Bend at the knees!” But I don't always know what my arms and legs are up to, not exactly. For me, I have no clear sensation of where my arms and legs are attached, or how to make them do what I'm telling them to do. It's as if my limbs are a mermaid’s rubbery tail. – Naoki, p. 37

3.8.2 Autism inside my brain

In addition to describing life in their bodies, the youths provided descriptions that related to brain function. They wrote about forming and retrieving memories, taking in the world through their senses, and making meaning from what they take in. In their descriptions, they drew comparisons between the workings of their own brains, and how they expect this is different from what happens in the brains of people who don’t have autism.

3.8.2.1 I know my brain works differently

Carly, Tito, and Naoki consider autism to impact components of their brain function. All three describe how they perceive their thinking, perception and memory to be different from the thinking, perception and memory of other people around them.

Certain memories are too difficult to forget. When a memory is associated with some extreme sensory activity, it is often hard to forget. How can you remember things about such early days? Someone asked me. Blame it on my extreme sensory activities. It is the factor that led me to remember certain aspects of my early days, although I sometimes cannot remember who I met at the store just yesterday. -Tito, p. 84

We do remember what we did, when, where, who we did it with and things like this, but these memories are all scattershot and never connected in the right order. The trouble with scattered memories is that sometimes they replay themselves in my head as if they had only just taken place – and when this happens, the emotions I felt originally come rushing back to me like a sudden storm. -Naoki, p. 31
3.8.2.2 I take in the world differently

Naoki, Carly, and Tito give descriptions of how they take in the world through their senses. Just as they do in their descriptions of attention and memory, they present their ways of processing sensory information in comparison to how they might be different from the experiences of neurotypical people.

*We see different than everyone else. We take pictures in our heads like a camera. It’s like filling a camera with too many pictures, it gets overwhelming.* – Carly, p. 182–183

*One moment you may look at a picture, and at the same time you are aware of the pink wall around the picture, you are also aware of Jack’s voice explaining something about the picture. The very next moment you are looking at the reflection through its glass frame, which is competing for attention while you are looking at the picture. You may see part of the room reflected in the glass, and you may be so absorbed in the reflection that you may not hear anything more from Jack’s voice because you suddenly discover that those reflections are conspiring to tell you a story.* – Tito, p. 52–53

3.8.2.3 Autism gives me gifts you don’t have

While discussing the things that make them unique and even blessed thanks to autism, Carly, Tito, and Naoki all describe certain benefits to their ways of perception and thought.

*When I realize my ability to interact with the shadows around me or the world of stories that appear to be forming behind a mirror, unbound by the laws of the physical world, when a little girl’s giggles color the walls and ceilings with rainbow foam when she is amused by my echolalia because I am a mirror to her words, I feel blessed for being what I am.* – Tito, p. 217

3.8.3 Autism from the outside

Throughout their memoirs, Carly, Tito, and Naoki discuss their autism in terms of how it impacts their relationships with other people: the way they believe themselves to be perceived by friends, families and professionals as well as their own emotional responses to this.
3.8.3.1 People assume I’m dumb

One reaction described frequently by all three youths, is that people around them consistently and constantly underestimate their intelligence.

*People just look at me and assume that I am dumb because I can’t talk or because I act differently than them.* – Carly, p. 234

*I guess this is because we seem to act younger than our true age, but whenever anyone treats me as if I’m still a toddler, it really hacks me off. I don’t know whether people think I’ll understand baby-language better, or whether they think I just prefer being spoken to in that way.* – Naoki, p. 22

3.8.3.2 I know how professionals see me

Carly, Tito, and Naoki’s descriptions show insight as well as a bit of cynicism. Carly and Tito in particular, express distrust and frustration with clinicians and other autism “experts”.

*No one wants to do something and then realize they did it wrong. However it is better to be wrong at home than in front of one of those clinical psychologists who assess your intelligence not by what you think but what you can do.* – Tito, p. 43–44

3.8.3.3 I know my autism is hard on you

The three youths repeatedly describe insights into how their autism [and especially their own behavior] impacts other people.

*I want to be able to go to school with normal kids, but not have to worry about them getting upset or scared if I can’t help myself and I hit a table or scream.* - Carly, p. 300

3.8.3.4 It is critical to be understood

Carly, Naoki and Tito highlight the ability to communicate with others as being crucial. They describe it as a way to connect with others, a source of validation of their intelligence and even a way to be acknowledged as human.
I don't know why we can't talk properly. But it's not that we won't talk - it's that we can't talk and were suffering because of it. All on our own, there's nothing we can do about this problem, and there were times when I used to wonder why Non-speaking Me had ever been born. But having started with text communication, now I'm able to express myself via the alphabet grid and a computer, and being able to share what I think allows me to understand that I too exist in this world as a human being. – Naoki, p. 24

I needed people to believe that they were my very own stories because I had the proof of my handwriting. If they doubted it, they could see me write my words. I knew very early on in life that if you happen to be born with autism, you will need to give plenty of proofs to doctors, psychologists, teachers, therapists, disbelieving uncles and neighbors and who knows who else? – Tito, p. 157

3.8.3.5 I get so embarrassed

Each of the youths describe moments of humiliation. This is sometimes linked to difficulties with control and then regret for an action. Other times this is linked to being misunderstood. Still other times, the youths feel embarrassment based on the assumptions other people make of them.

I’d be okay with my weird voice on my own, but I’m aware that it bothers other people. How often have the strange sounds coming out of my mouth embarrassed me nearly to death? Honest, I want to be nice and calm and quiet too! But even if we’re ordered to keep our mouths shut, or to be quiet, we simply don’t know how. Our voices are like our breathing, I feel, just coming out of our mouths unconsciously. – Naoki, p. 20

3.8.4 My inside and outside do not match

The meta-theme My Inside and Outside Do Not Match reflects the over-arching problem described repeatedly by all three youths. Because they struggle to control their bodies, because they cannot communicate verbally, because their brains work differently, because people assume they are unintelligent, their external selves (what others see, hear, and presume) misrepresent their internal selves (what the youths want and understand and how they see themselves). The
following quote is a recollection Tito has from his school days which offers a powerful illustration of several of the themes presented in this analysis, culminating in an example of how the way he is perceived from the outside does not match the person he is on the inside.

*Teachers did not really know what to do with me throughout my day. So they gave me markers and papers and crayons and all that junk to make a Picasso out of me, if they wanted me to be one at all, or to try to keep me occupied. I must admit that I cannot draw beyond stick figures. Every time I tried drawing something I would get so embarrassed. I had no mental model or map in my mind, and did not really know what I was drawing. And when teachers tried to be dishonest about it by praising me with a “Good job” I was more humiliated. Do they not know that I have two books published and one translated into German? Why didn't I tell them? The answer is not simple. I wish I could initiate my wishes more than I could initiate my impulses. I wish I could write and communicate in every circumstance, no matter what. But if I could do all that, I certainly would have something other than autism. – Tito, p. 80–81*

### 3.9 Discussion

This thematic analysis gives a rare glimpse into ways three youths who have severe autism and are minimally verbal, experience and understand their diagnosis. Carly, Tito, and Naoki both explicitly and implicitly offer perspectives that sometimes support, sometimes challenge dominant academic and clinical concepts and theories. Examined in the context of relevant autism literature, some interesting highlights arise.

The experiences and perspectives described in the theme *Autism inside my body* align well with literature pertaining to proprioception (Riquelme, Hatem, & Montoya, 2016) and dyspraxia (Dziuk, Larson, & Apostu, 2007) for people who have autism. There is also a growing portion of the autism literature which identifies movement control difficulties (including movement inhibition and initiation) as an important component of autism for at least some people (Donnellan et al., 2013; Miyahara, 2013; Robledo et al., 2012; Savarese, 2013). Indeed, there has even been debate in the literature as to whether movement difficulties should be considered a core feature of autism (Fournier et al., 2010; Miyahara, 2013; Robledo et al., 2012; Savarese,
While this debate is ongoing in the literature and might not be highly relevant to some people with autism, Carly, Tito, and Naoki have discussed movement control difficulty as central to their experiences of autism and their primary barrier to function.

Further, Carly’s, Tito’s and Naoki’s experiences of sensory perception factor frequently into their descriptions of everyday life. Despite this being a theme common to all three, each youth describes sensory experiences differently. Much of their experiences align with descriptions of hypersensitivity and hyposensitivity to sensory stimuli seen in the literature on sensory processing disorder (DeBoth & Reynolds, 2017). Tito stands out in his description of sensory experiences in that he adds semantic meaning and lyrical description. For example: *... Jack’s voice because you suddenly discover that those reflections are conspiring to tell you a story.*

The sub-themes described within *Autism from the Outside*, are relevant to the large and complex body of literature pertaining to the construct Theory of Mind (TOM) and autism. TOM is interested in a person’s ability to hypothesize on the thoughts, feelings, and intentions of others (Baron-Cohen, Leslie, & Frith, 1985). The deficit in Theory of Mind theory is among the most frequently researched explanations for core symptoms of autism (Rao, Mysore & Raman, 2016). Impaired TOM has been presented in some instances as a unifying explanation for the social and communication difficulties experienced by people with ASD (Baron-Cohen, et al., 1985; Rao et al., 2016). However, Tager-Flusberg (2007) has presented a more complicated dynamic than this and challenges the notion that deficits in TOM are universal to people with autism. Additionally, Tager-Flusberg (2007) notes that skills in TOM are closely linked to language development. Perhaps it is because Carly, Tito, and Naoki have strongly developed (nonverbal) language that they have developed the skills in TOM that are evident in their writings (which contain much conjecture of other people’s thoughts, intentions, emotional responses, and cognitive processing).

Amidst discussions of how their own intelligence is underestimated by clinicians and educators, Carly, Tito, and Naoki postulate that other people who have severe autism and are nonverbal may have similar experiences. Predominantly, autism literature would support the assumptions held by the professionals working with Carly, Tito, and Naoki: that people who present as minimally verbal and who require support for daily living activities have low intelligence and limited understanding of their environments (Grondhuis et al., 2018). In 2014, the Centers for Disease Control and Prevention estimated that 50% of people with an autism spectrum disorder
have below average intellectual functioning (CDC, 2014). The literature does recognize intelligence to be one of the most heterogeneous aspects of people on the autism spectrum and recent research suggests that verbal skills and intelligence may not be as strongly associated as previously thought (Munson et al., 2008). Grondhuis and colleagues found that language demands of certain intelligence tests significantly impact scores for children with autism and recommend very cautious application and interpretation of intelligence tests with this population. Until innovative methods for assessing intelligence with people who are minimally verbal become widely available, the extent to which Carly, Tito, and Naoki are unique in this regard, will remain unclear (Tager-Flusberg et al., 2017; Tager-Flusberg & Kasari, 2013).

Carly, Tito, and Naoki each describe difficulties with social interaction that align with the diagnostic criteria for ASD (APA, 2013), so far as to say that they do have difficulties establishing and maintaining social relationships. Where these youths’ accounts diverge from some tenets within autism literature (and even from the DSM-5 guidelines) is in their explanations for these social difficulties. Whereas the DSM-5 guidelines link difficulties with social relationships to factors such as limited interest in others, lack of understanding of social conventions, and limited recognition of social emotions (Carpenter, 2013), these youths link their social difficulties to struggles controlling their bodies and resultant unintended, at times inappropriate, behaviors. The youths’ descriptions are more aligned with Casartelli, Molteni, and Ronconi (2016) who, based on their review of electrophysiological and neuroimaging studies, suggest that “motor cognition anomalies” can explain ASD difficulties in social interaction.

The experiences and perspectives described in the meta-theme Inside and Outside do not match parallel descriptions found in elements of the critical disabilities literature which, among other things, explores the phenomenon in which people who identify with a disability face faulty and harmful assumptions (Hammell, 2006). The types of stigma and underestimation from others that Carly, Tito, and Naoki have described can also be found in qualitative health research with people who have motor impairments (Imms, 2008; Lindsay, 2016; Maffoni et al., 2017), craniofacial differences (Masnari et al., 2013), and mental illness (Ilic et al., 2014). Further, the frustration and cynicism that Carly, Tito, and Naoki express with respect to clinical and academic experts in the field of autism, is consistent with findings from Pellicano and colleagues in their work exploring views of people in the autism community in the United Kingdom (2014a&b).
We acknowledge that these findings challenge the common assumption that people who do not acquire verbal speech do not have the capacity to render sophisticated written material. We know that some people will therefore question the authenticity of authorship of the memoirs we selected for this study. We accept the authenticity of authorship in these memoirs based on the following publicly available information: all three youths have been featured in online and television reports and interviews which include video images of them typing. There is also video footage of Tito writing with a pencil and National Geographic Online Magazine article (March 2005). In which the reporters describe Tito’s appearance, observable behaviors, and writing. Carly and Tito have been filmed giving interviews with reciprocal, real-time questions and answers. Naoki has been featured in newspaper articles in which he was interviewed directly.

It is also worth noting that in addition to disclosures of an autism diagnosis within their memoirs, news segments can be found featuring Carly and Tito that include testimonies from a psychologist and a physician who confirm their diagnosis and their abilities to communicate via typing (Carly) and writing (Tito). Web reports and online newspapers discussing Naoki and his publications include statements from clinicians also confirming his diagnosis.

3.10 Practice-Based Considerations

Carly’s, Tito’s, and Naoki’s descriptions of how they are perceived by others from the outside does not match what they feel, understand, and want on the inside, should give pause for thought to professionals. For all three of these youths, this inside-outside mismatch contributed to clinical errors within the common practice of using observable behaviors to assess things such as intelligence. Recall Tito’s description “… one of those clinical psychologists who assess your intelligence not by what you think but what you can do” (p. 43). Risk of this kind of professional error may be minimized by practices such as gathering varied assessment information, using multiple tasks over multiple visits and multiple settings, as well as working to establish effective communication with clients/students to augment their observational assessment findings.

The emphasis these youths have placed on controlling their bodies suggests that movement control and mind–body connection may be a helpful avenue for intervention. Perhaps this link holds a portion of explanatory power for the benefits seen in some studies exploring yoga (Koenig, Buckley-Reen, & Garg, 2012) rhythm (Berger, 2013), sensorimotor (Shoener, Kinnealey, & Koenig, 2008), and music and movement (Srinivasan & Bhat, 2013) based
interventions for people with autism. Finally, many professions promote values pertaining to “person-centered practice”. Such practice should be based on evidence that includes client perspectives (Whalley Hammell, 2013 & 2015). Since qualitative research in the field of autism, especially work that explores perspectives on the severe end of the spectrum and who are minimally verbal (Tager-Flusberg & Kasari, 2013), is scant, it is worthwhile to consider the perspectives of these youths in the pursuit of client-centered care.

3.11 Strengths and Limitations

The themes and concepts presented in this analysis highlight insider perspectives that may be helpful in interpreting and applying complex academic literature, stimulating critical thinking, and gathering evidence for practice. This study lays groundwork for future research that is in line with priorities expressed by people with autism and their families; namely, research that seeks to promote better understanding of autism for clinicians, academics, and the general public (Pellicano, Dinsmore & Charman, 2014a&b).

It is of note that the data set was composed of published memoirs that had undergone editing processes with marketing goals in mind. Naoki’s book has been translated from Japanese to English by an author who has a son with autism. None of these authors communicate verbally and did not “narrate” their accounts for publication. As these data were generated from extant texts rather than interviews, there was no opportunity for probing questions or dialog. This study does not generate the sort of evidence required for changing practice protocols, however, it does offer clinicians and educators a fresh take on how autism is understood and experienced by at least a few people who have it.

3.12 Future Directions for Research

Further research can help answer lingering questions such as “Just how unique are the experiences and perspectives of these youths?” and “How would people with autism respond to this analysis?” Our findings support the need for further research into brain-body connection and possible interventions. Both movement-based (Caro et al., 2017) and cognitive-based (Phelan, Steinke, & Mandich, 2009) interventions show promise and warrant further study. It is critical to move toward developing new evidence-based intervention options as soon as possible, as many families currently spend large sums of money on interventions with little evidentiary support
The work of Tager-Flusberg and colleagues (2013, 2017), to find novel ways (such as eye tracking, electrophysiological monitoring, and brain imaging) to assess the understanding, interests and intelligence that exist “inside” people who have severe autism and are nonverbal is critical and offers hope to improve our understanding of this sub-population of people with autism who have, to date, been left out of most research. If the patterns we’ve discussed in this analysis are also seen in larger data sets, they could have important clinical implications pertaining to assessment as well as approaches for intervention.

3.13 Conclusions

Insider perspectives are an important resource for interpreting and applying academic literature in the pursuit of evidence-based practice (Davies & Gray, 2017). With respect to pursuing evidence-based practice in the field of autism, insider perspectives may be particularly helpful to improve our overall understanding of autism since autism literature is known to be complex, confusing, and sometimes contradictory (Ashburner, Rodger, Ziviani, & Jones, 2014). This analysis of memoirs has provided a glimpse into the way these three youths understand their own diagnosis. Since insider perspective is uncommon in academic autism literature, it offers us important insights. It reinforces the need for further research to improve our understanding of first-person experiences with autism to more fully inform professional practice. Most significantly, it suggests that when it comes to people with autism, what we see on the outside (e.g., looking away rather than making eye contact) may not be a good indication of what exists on the inside (e.g., interest in social connection). As Leary and Hill suggest (1996, p. 4) “It becomes necessary to suspend absolute trust in one’s intuitive interpretation of actions and intent. Behaviors may not be what they seem”.

3.14 Acknowledgements

We thank Carly, Tito, and Naoki for sharing their perspectives and experiences with courage, candor, and thoughtfulness.

3.15 Disclosure statement

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Chapter 4
Living in Autistic Bodies: Lessons from bloggers

This chapter has been prepared for submission to the journal Focus on Autism and other Developmental Disorders. In it, I report on a study that sought to gain insider autism perspective by examining blogs written by autistic people. The manuscript will be submitted after final defence to allow an opportunity to include all feedback during the dissertation from examiners. I, Christie Welch, completed work under the guidance of Dr. H. J. Polatajko, Dr. P. Rigby, Dr. M. Fitch and Dr. D. Cameron.
4 Living in Autistic Bodies: Lessons from bloggers

4.1 Introduction

In this article we report on findings from a study designed to address the questions “Do bloggers who self-identify as autistic discuss embodied autism and being misjudged?” and if so, “Do their discussions serve to deepen our understanding of these concepts?”. The study builds on the findings of Welch and colleagues (2018), which examined three memoirs written by autistic youths. Welch and colleagues found that the young memoirists described an over-arching problem in which the way they were perceived by others from the outside did not match the people they felt themselves to be on the inside. When accounting for this problem, the youths gave primacy to embodied experiences of autism and difficulty controlling their bodies: particularly initiating desired movements and inhibiting unwanted movements (Welch et al., 2018). In the study reported here, we sought to deepen understanding of embodied experiences of autism by examining how autistic bloggers describe and understand it.

4.2 Background

Autism is intensely researched around the world, with new discoveries being made continuously (Amaral, 2011). Especially numerous are recent discoveries pertaining to autism etiology and biomedical issues (Amaral). It is well documented that most autism research to date has been conducted within the traditions of basic science, with a focus on biomedical factors (Amaral; Pellicano, Dinsmore & Charman, 2014a&b; Tager flusberg & Kasari, 2013; Tager flusberg et al, 2017). Verhoeff suggests that the current “unremitting search for the neurobiological basis of autism” has distracted researchers from focusing on experiences of impairment and distress and has ultimately limited our understanding of autism and its related behaviours (p.443). Pellicano, Dinsmore and Charman (2014a&b) have also taken this standpoint and suggest that autism

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1 In this article, we have chosen to use “identity first language” in recognition of the preferences stated by the informants in this study as well as recommendations made by autism self-advocates (Owren & Stenhammer, 2013)
insider perspective is the element most urgently needed to improve current understanding of autism.

The biomedical focus of autism research to date and the related limitations in research outcomes have not escaped the notice of the autism community. Pellicano, Dinsmore and Charman (2014b) conducted a large (N=1929) survey of the autism community in the United Kingdom, including autistic people, parents and professionals. The survey results were supported by interviews and focus groups. The respondents acknowledged the biomedical and epidemiological focus in research and expressed disappointment in this lack of breadth. The respondents reported a desire for autism research to focus upon matters of importance to them today, such as daily living skills, access to employment and the functional challenges they identify as important: particularly sensory difficulties, multi-tasking and anxiety (Pellicano et al., 2014b). They also stressed the importance of research that can inform evidence-based interventions and more accurate public awareness of autism.

The scarcity of research examining autistic insider perspective has been linked to difficulties conducting interviews with autistic people, since difficulty with communication is a core characteristic of the diagnosis (Anagnostou et al., 2014; Preece & Jordan, 2010). Early attempts at interviews found that participants became distressed as well as had difficulty recounting past events, talking about their emotions, and answering open-ended questions (Preece & Jordan, 2010). Research engaging autistic people who are minimally verbal has been considered especially unfeasible, and the perspectives of this portion of the autistic population is almost completely absent from the academic literature (Tager-flusberg & Kasari, 2013; Tager-flusberg et al, 2017). Welch and colleagues (2018), generated one of the few examples of such work by drawing on memoirs written by minimally verbal youth.

With the emergence of the internet, a new forum for communication has presented itself for autistic people. Now, an increasing number of autistic people are sharing experiences and perspectives online (Gillespie-Lynch, Kapp, Shane-Simpson, Shane Smith & Hutman, 2014). Autistic people report numerous benefits of online communication, including increased comprehension and control over communication, finding others with common experiences, and ability to express their true selves (Gillespie-Lynch et al., 2014; Nguyen, Duong, Phung, & Venkatesh, 2014). One increasingly popular form of online communication is blogging.
Blogs are personal online journals where entries are posted chronologically (Hookway, 2008). They offer rich opportunities for researchers, combining the far reach of technology with the rich content of diaries (Hookway, 2008; Salmons, 2012).

Given the gaps in current understanding of autism and the related paucity of insider perspective within the academic autism literature, we embarked on this research with the objective of building an understanding of insiders’ perspectives of autism. This research built on the findings of Welch and colleagues (2018), which found that the autistic youths whose writings were examined experienced a problem of being misjudged by others. The youths in that study linked this problem to a misleading outward appearance that was caused by bodies they could not control well. Specifically, the youths described difficulty initiating movements they wanted to make and inhibiting movements they did not want to make (Welch et al., 2018). The availability and suitability of blogs written by autistic people, offered an important opportunity to access the insider perspectives of a large number of autistic people, in written form that has not been subjected to professional editing by publishers. We were curious to understand whether the experiences identified by Welch and colleagues (2018) were unique to the memoirists whose works were examined or if other autistic people were also discussing similar phenomena. Our research question was; “Do bloggers who self-identify as autistic discuss embodied autism and being misjudged?” and if so, “Do their discussions serve to deepen our understanding of these concepts?”.

4.3 Methods

4.3.1 Purpose

In this study we sought to understand the insider perspectives that self-identified autistic bloggers offer on experiences of embodied autism and being misjudged. We aimed to deepen understanding of these concepts, making them more precise, more complete and further supported by more description.

4.3.2 Approach

In this study, we took a descriptive qualitative approach to gain understanding of perspectives of our informants. Descriptive qualitative research examines events and activities in an in-depth and
immersive way. Within this approach, the aim is to provide a thoughtful account of events or experiences, in a way that stays close to the interpretations ascribed by the informants (Sandelowski, 2000).

4.3.3 Data source and selection

We chose blogs written by self-identified autistic people as the data source. Blogs are personal online journals where entries are posted chronologically (Hookway, 2008). Blogs capture experiences in real time, protecting content from memory issues (Hookway). The way bloggers share experiences, identities and thoughts, situates data within detailed context (Hookway), which is important for understanding phenomena (Charmaz, 2006). In recent years, blogs have gained recognition as a valuable source for data in social and health research (Braun & Clarke, 2006; Hookway). They offer rich opportunities for researchers, allowing them for geographic reach as well as rich content (Hookway; Salmons, 2012).

For this study, we sourced blogs through the “blog hub” (a curated site that serves as a blog directory or search engine) called Actually Autistic (Actually Autistic, 2018). The operators and curators of this hub provide lists of and links to blogs written by autistic people and autism allies. The hub offers demographic information (when provided by the blogger) and identifies whether the blogs are written by an autistic person or an ally and whether the blog is specifically about autism or other topics.

Blogs were included for data extraction if they were written in English, by people who self-identify as autistic, of any culture, gender, geographic location or level of severity on the autism spectrum. We did not include blogs written by parents, clinicians or scholars, if they did not identify on the autism spectrum themselves. Using terminology from Braun and Clarke (2006), we refer to all data collected for the research project as the data corpus and all the data from the corpus that were used for this analysis as the dataset. A list of all sites sampled for the data corpus can be found in Appendix A. Figure 1 depicts a numeric description of demographic characteristics of blogs sampled to create the data corpus.
4.3.4 Data generation

Data were generated through “blog trawling”, Hookway’s (2008) term for searching blogs for content relevant to the phenomena under study, and “scraping”, Roberts & Sipes (2018) term for cutting and pasting content from online sources to offline digital storage dataset. Based on recommendations from Hookway, we set two clear parameters for blog trawling. First, we set a time limit of 40 hours; second, we set a scoping limit of reading the three most recent posts per blog, as well as use of within-blog-search-function if available. Hookway (2008) identified such parameters as important to avoid unreasonable amounts of time searching each website for related content. At each blogsite, the first author scanned the three most recent posts, looking for discussion of embodied experiences of autism, issues of movement control, and experiences of being misjudged or misinterpreted. If the blog had a search function, the first author searched the site using the following terms: “body”, “control”, “misjudge”, “misunderstand”, “underestimate”, “assume”, “assumption”. The terms “inertia” and “mind-body” were added after initial searching uncovered these as frequent descriptors of the phenomena of interest. When content discussing embodiment or being misjudged was found, the content was scraped and added to the data corpus.

Our protocol was to evaluate the trawling procedure as well as the quality and quantity of data following 40 hours, and to proceed with additional trawling if needed. Thirty-seven of the blogs
were directly sourced from the hub Actually Autistic (Actually Autistic, 2018) and three blogs were added through “snowballing”, using links from within one blog to the next.

Throughout blog trawling, a descriptive documentation chart was used to record details such as blogger gender and location (where known), stated purpose of the blog (where available) and the topics of the three most recent posts on the blog. Reflexive memoing was conducted throughout trawling, as suggested by Charmaz (2006), to document researcher responses to data, development of ideas and research decisions.

After the set trawling period, the first author conducted an open read of the data that had been generated and presented a summary to the research team. We found it offered a rich description of the phenomena of interest. We also found compelling discussions of how these bloggers understand autism and its related behaviours, offering explanations of autism that seemed novel and important, but did not pertain directly to our phenomena of interest. At this point, we decided to conduct two separate studies with this data corpus. The analysis presented in this article focuses on embodied experiences of autism. A complementary paper (Welch, Rigby, Fitch, Cameron, & Polatajko, 2019a) reports on a separate analysis which focused on the bloggers’ ways of understanding autism and their explanations for autistic behaviours as well as their experiences of being misjudged.

Following the open read, we decided to begin analysis while remaining open to the possibility of additional data generation or data exclusion, as recommended by Braun and Clarke (2006). After two rounds of coding, we were satisfied that the dataset could provide sufficient description and detail for the objectives of this research and no further data were generated.

4.3.5 Data analysis

The analytic lens used within this study was shaped by our application of a qualitative descriptive approach. We aimed to generate a thorough analysis that leaves intact the interpretations that informants have attached to events. Since we were approaching the data with very specific phenomena of interest, we conducted a directed content analysis. A directed content analysis is a more structured and deductive process than seen in a conventional approach (Hickey & Kipping, 1996). Directed content analysis is useful when preliminary research on a phenomenon is incomplete or would benefit from further description (Hsieh & Shannon, 2005).
It can be used to validate or to conceptually extend an early description of phenomena (Hsieh & Shannon), which made it a good fit for the objectives of this study.

To embark on the directed content analysis, we began with a codebook of a priori themes (Appendix B) that were taken from Welch and colleagues (2018). As suggested by Brooks, McCluskey, Turley and King (2015), we took a flexible approach to applying the codebook, developing themes most extensively where the richest data (in relation to the phenomena of interest) were found. In this approach, new themes may be inserted, and existing themes redefined or removed if they seem superfluous.

Analytic strategies followed structure provided by Braun and Clarke (2006); a recursive process of coding, collating, mapping, reviewing, and creating clear themes. Just as was done throughout data generation, the first author used reflexive memoing throughout analysis as recommended by Charmaz (2006).

4.3.6 Ethical considerations

In this study, we approached the blogs as published documents. We also treated the blogs as fully public based on Willis’ (2018) criteria for publicness of online material. We only used blogs that spoke to a public audience (which was usually explicitly stated on the blog home pages), that did not have “members only statements”, and did not require passwords for use (Willis 2018). There are two major ethical implications of this stance. The first is that the bloggers whose writings were sampled are seen as “authors” not “participants”. As such, their writings are cited as per copyright and APA guidelines. This means that the bloggers’ virtual identities (which sometimes coincide with their IRL identities) are revealed within this research. Additionally, the data have been generated, analyzed and presented in this report without the informed consent of the bloggers. The decision to proceed without informed consent was based on two rationales: 1) Since many blogs have no method to contact the authors, and since many of those that do go for extended periods without updates (and presumably without checking for requests from visitors), the requirement of consent would greatly reduce the quantity and quality of the data and ultimately the scientific value of this study, and 2) The blogs we sampled explicitly express desire to raise awareness and understanding of autism and to reduce autism’s stigma. We believe this research to be aligned with the intentions of how the bloggers wish their writing to be used.
This study received ethics approval from the Health Sciences Research Ethics Board at the University of Toronto.

### 4.4 Findings

A primary finding from this study is that themes of embodiment and being misjudged are being discussed by these bloggers and are not limited to the memoirists sampled by Welch and colleagues (2018). This article focuses on the portion of the analysis which pertains to embodiment. Themes pertaining to being misjudged are explored in a complementary paper (Welch, Rigby, Fitch, Cameron, & Polatajko, 2019b)

This analysis uncovered widely varied perspectives and has facilitated a conceptualization of embodied autism that is at once broader and more refined than that of our earlier work. In this analysis, we generated two overarching themes pertaining to living in autistic bodies. The first overarching theme relates to the ways embodied autism impacts movement. The second theme relates to the ways embodied autism impacts arousal-regulation. In this article, we use the term “arousal-regulation” to refer to a person’s ability to govern his or her own physiological and psychological activation level (which can range from deep sleep to intense excitement), for the purpose of adaptive functioning (Gould & Udry, 1994). Figure 4-2 represents a thematic map generated during the analysis.

**Figure 4-2 Thematic map**
4.4.1 Moving an autistic body

Living in an autistic body requires moving an autistic body. According to the bloggers in this study, moving an autistic body entails difficulty starting movements, stopping movements, coordinating movements, and making movements match intentions. They suggest that this is made difficult, at least in part, by 'poor brain-body connections'. The bloggers define these issues and discuss their functional, social and emotional impacts suggesting that they 'can’t start', 'can’t stop', experience 'swapped response' and 'move differently' because of body-mind disconnect.

4.4.1.1 Can’t start

The bloggers described difficulties initiating movements with their bodies. Despite having mental plans that they wish to execute, their bodies at times remain motionless. This can lead to complete barriers to function and feelings of being trapped.

*I still cannot adjust my blankets in bed or even initiate moving to get another blanket if I am cold. Does that mean I’m too stupid to identify how I feel? No, it means I can’t get my body to do what I want it to do, when I want it to, with reliability and consistency. This is entrapment. It is not receptive and expressive language confusion, and most definitely not a lack of thought, emotions and awareness. (Kedar, 2015)*

The bloggers discussed that when an autistic body won’t start, it can impact a wide variety of functional tasks, including speaking.

*When I lose the ability to speak, I can think about the sounds that I want to create. I can think about the ways my mouth and throat and lungs move when I generate those sounds. But I cannot will my body to speak. It is as baffling to me as it is to those around me, but I can think the words — I can even type the words — but I cannot speak the words when I am in a state of “speaking inertia.” Just as there are times when those around me feel I might never shut up, there are times when it seems I might never speak again. (Sparrow, 2016)*
4.4.1.2 Can’t stop

Difficulties inhibiting or stopping unwanted movements are discussed on the blogs with great frequency. Having a body that won’t stop causes frustration and embarrassment for the bloggers.

*My body edits not. It goes places by itself without listening to me. To be in a rude body is awful.* (Stup, 2017)

The bloggers suggest that difficulty stopping movements causes them to “look different” from non-autistic people, which can be socially isolating. They suggest that it also causes other people to misinterpret the bloggers’ behaviours.

*People with autism sometimes do weird or different movements with their bodies. This is weird to most people, but not to autistics like me. Sometimes our brains make us do moves that we can’t help or stop. Understand that it’s utterly not bad behavior, it’s how we process lots of information.* (hdawg99, 2017)

For some bloggers, this problem is so persistent, it limits functioning in almost all areas of life. This causes them mounting frustration and anger which further reduces movement control.

*I am angry at my body because it will not do what I want it to do. I have a brain body disconnect that makes me so upset because I cannot make my body do what I tell it to do. For example, I know how to shower but I cannot think my body parts into doing the simple steps. I know how to type but I cannot stop touching the same button over and over again. This makes me so angry. My anger is my downfall because I am intelligent (and know better) but when I get angry, I lose even more body control and I hurt people.* (Harbin, 2017)

4.4.1.3 Swapped response

The bloggers describe mentally intending one motor response, and then observing their bodies execute a completely different motor response. This makes it incredibly difficult for them to complete desired tasks and to present their true intentions and awareness to other people.
Tonight my dad asked me to set the table for dinner. My mind knows where each person sits. I give myself the order to make plates go to each person. I plan to carry out the order from dad. However, my feeble body balks at this order. It wants to put all the plates on one end of the table and the cups on the other end. I end up looking like an idiot who can’t understand the concept that everyone is supposed to get their own place setting. I want my body disciplined to follow the rules. How do I get my body to cooperate? This is my biggest struggle. (Reyes, 2017)

The bloggers also describe completely swapped verbal responses. They report this causes them great difficulty with communication and embarrassment and frustration

Many times I say nonsensical things like, “Larry boy!” or “Go back to green house!” and I repeat it many times for no reason. I hear myself and think, boy, I sound ridiculous; and I wish I could stop but I have no control. When people ask me things I know exactly what I want to say, but there is an ever-present blockade between my brain and my mouth. It is extremely frustrating as you can imagine. (Roses are red for autism, 2015)

4.4.1.4 Moving differently

According to the bloggers, coordinating movement can be difficult in an autistic body. The bloggers describe a range in severity of coordination problems as well as a wide array of impacts. In addition to impacting physical function, the bloggers often discussed social impacts of moving differently, such as limitations in choice for clothing and accessories.

I am autistic. Just like the screenings warn, I walked on my toes when I was little, and until I hurt my ankle this summer, I still did. I can dance, kind of, not really. In my own way. I have a lot of trouble with conventional femininity: I wear long skirts and long hair after a religious upbringing, but I don’t have the motor skills or the patience or the social-cognitive something for most of the work required to do femme traditionally. I can’t put on my own makeup or paint my nails; I can’t fasten any clothes that a typical six year-old can’t. I used to be able to pin up my braids, but I lost that skill sometime last year after
going too long without OT. The day you see me with my hair perfectly coiffed and my eyes carefully made up, in a coat that buttons and boots with no zippers, is the day you know I’ve either been married or placed on a Medicaid waiver. (Bascom, 2016)

For many bloggers, moving differently is a constant source of stress and social pressure.

*I have to constantly feel terrible about myself because of the way I walk and feel like I’m so much worse than practically everyone I know just because I’m stimmy and sometimes trying not to be stimmy and my proprioception is terrible so all my movements are very dramatic.* (Forest, 2010)

### 4.4.1.5 Brain-body disconnect

The bloggers link their movement difficulties to poor connections between their brains and their autistic bodies. They say that brain-body disconnect impacts their daily functioning.

*Personally, body awareness is a really big deal for me: I run into door frames and furniture, misjudge steps and ledges, over- and under-reach when picking things up and drop them because I misjudge how firm a grip I’ll need to hang onto them. My sense of where my body ends and the way it moves is really quite limited.* (Letters from Aspergia, 2012)

Some bloggers see brain-body disconnect as the source for their unusual movements.

*Proprioception is my biggest problem. My body does not feel where it is in space. I make many movements I don’t want to make but I am compelled to do it so I can feel my body. I must tap or twirl something in my hands to feel them. I often rock or pace to feel my core. Independent motor planning of my body is difficult for these reasons.* (Reyes, 2017)

### 4.4.2 Regulating an autistic body

According to the bloggers in this study, autistic bodies are hard to regulate. Autistic bodies can sometimes be so over aroused or so under aroused that completing tasks of daily living becomes impossible.
4.4.2.1 Meltdowns

According to the bloggers, autistic bodies are prone to meltdowns. In the bloggers’ descriptions, a meltdown is a phenomenon which causes a person with an autistic body to feel completely overwhelmed and out of control. This loss of control links their meltdowns to the overarching theme of “moving an autistic body” as well.

*It is the most intense feeling when I get overwhelmed. How do I describe it in polite terms? It is like the need to vomit. Do you think you have the ability to hold that in? Like it or not, the vomit insists on being released. The need to purge is stronger than manners, or place, or doing what is appropriate. The body defeats the mind’s wishes.* (Kedar, 2012)

According to the bloggers, meltdowns are expressed in various forms but are generally the result of multiple stressors combined. Factors such as anxiety, sensory processing difficulties, social demands and autistic burnout combined with the frustration and humiliation of communication difficulties are described as common contributors to a meltdown state.

*Meltdowns can affect any age of individual on the autistic spectrum, they are not the preserve of the child! They aren’t tantrums, the reasons for them are totally different and they are not about demanding attention or histrionics. Stress over something builds up, it can be anything, autistic people are all different and have different triggers. For me, people refusing to listen or understand me is a difficult one, as well as noise, or feeling trapped or controlled. You feel something bubbling up inside you that you don’t have any control over, you feel panic and you want to flee the situation/trigger. ...If you are trapped in the situation, despite your best efforts, and especially if it involves sensory overload, that meltdown will come.* (Planet Autism Blog, 2014)

4.4.2.2 Autistic Inertia

“Autistic inertia” is a common topic of discussion seen in the blogs. The bloggers describe autistic inertia as an extended state of being unable to do the things they want to do because they are inexplicably “stuck”. They are frozen by a force that is partly “mental”, but largely physical.
Autistic inertia is described as having similarities to “can’t start”, but whereas “can’t start” happens sporadically and briefly in the context of executing a specific movement, autistic inertia is described as a state which causes extreme inactivity for extended periods. Bloggers describe experiences of autistic inertia to varying degrees, durations and frequencies, but all agree that when it strikes it can be debilitating.

*Autistic inertia is common but little-known and poorly understood. It lies somewhere on the borderline between catatonia and executive dysfunction. Inertia doesn’t mean laziness, or not wanting to do things, or procrastinating – although it can look like all of those things. (Autisticality, 2014)*

Bloggers describe inertia as having an episodic quality that comes and goes without clear patterns or causes and leads to fluctuations in performance on tasks.

*An autistic person might be able to do something easily one day but run up against severe inertia with the same task on another day. Autism isn’t something constant and steady-state but rather something variable, more like multiple sclerosis, fibromyalgia, or lupus. What we can do one day, we can’t do every day. What we can’t do one day, we might be able to do on another. This, in my experience, has been one of the hardest things for people around me to grasp...Kalen [another autistic writer and blogger] describes inertia as “a combination of attention shifting and motor planning difficulties” which definitely resonates with my experience. There are times when I am only able to act by willing my body to perform and just as many times when I cannot get my body to perform, no matter how much will I exert. (Sparrow, 2016)*

**4.4.2.3 Autistic burnout**

Bloggers describe autistic burnout as something that is a uniquely autistic trait. Like autistic inertia, autistic burnout is described as having have an observable expression of decreased activity level. However, they attribute autistic burnout to a distinct source: severe exhaustion. They discuss this severe exhaustion as having uniquely autistic causes. One such cause the bloggers described is a constant battle with sensory overload.
The difference is that not everyone has the same amount of energy. The average able-bodied NT [neurotypical] person has plenty of energy to spare, so that they rarely ‘run out’. Most of the time they are perfectly able to have a full-time job, socialise, look after themself and their home, and pursue their interests and hobbies. The idea of a limited energy level that doesn’t simply result in sleepiness after a long day is difficult to understand if you’ve never experienced it…Burnout eventually does have the intended effect – it stops the overload. Because it stops my ability to function at all, which handily includes my ability to go to school or work or do the things that were draining my energy faster than I could replenish it. (Autisticality, 2015)

Another source for autistic burnout is described as constantly working to inhibit or initiate movements. What is described is an ongoing battle, fought in order to exhibit appropriate behaviour and to complete daily tasks.

I get overwhelmed with trying to control my body. I have to work so hard to get through my day. I am just trying to limit my movements so I can function at all (Reyes, 2014)

4.5 Discussion

In this study, we were curious to understand autism embodiment from an insider perspective. In pursuit of this understanding, we examined blogs written by autistic people. The findings in this study agree with those reported by Welch and colleagues (2018) and support the extension of the concept of embodied autism to include swapped responses and difficulties with arousal regulation.

The analysis generated multiple themes that pertain to movement-related and arousal regulation-related elements of embodiment. Movement related themes include difficulty stopping, starting and coordinating movement as well as execution of movements that do not match intentions. This finding adds to a small but growing body of literature acknowledging the impact of movement-based challenges for autistic people. It is relatively well established in the literature that people with autism can experience challenges in proprioception (Riquelme et al., 2016) and dyspraxia (Dziuk et al., 2007). Research has also begun to emerge suggesting that movement
challenges in autism can go far beyond impacts such as “clumsiness” to extend to profound impacts on daily functioning, verbal speech and quality of life (Bertilsson, Gyllensten, Opheim, Gard, & Sjödahl Hammarlund, 2018; Donnellan et al., 2013; Savarese, 2013). In a study that is highly relevant to and convergent with our findings, Bertilsson and colleagues (2018) combined qualitative interview with formal measures of body awareness and movement function. They found that the autistic young adults in their study experienced difficulties with body awareness, movement control, postural control, experiencing emotions as physical/embodied experiences, and fatigue. Additionally, their participants reported profound impacts of these embodied challenges to daily functioning and quality of life (Bertilsson et al., 2018). This growing body of literature challenges what Verhoeff (2013) has identified as the long-standing dominant framing of autism as primarily a condition of impaired social cognition and social interest.

This study has also generated themes of embodied autism that pertain to arousal regulation. These themes relate to patterns of being over reactive due to being over aroused and under reactive due to uniquely autistic states of exhaustion and “stuckness”. Using vocabulary from the bloggers themselves, we have named these themes autistic inertia, autistic burnout and meltdowns. Autistic inertia was a term and topic of discussion seen with very high frequency within the dataset, but we were unable to find this term within the academic literature. Autistic inertia relates most closely to descriptions found in the literature of “catatonia of autism spectrum disorders”, which is defined as a cluster of behavioural features affecting speech, movement and postures (Wing, & Shah, 2000). It is said to range from milder disturbances to complete absence of speech and movement (Wing, & Shah, 2000). “Catatonia in autism spectrum disorders” is not well understood and is considered to be a rare occurrence amongst autistic people (Baumer & Spence, 2018). The bloggers’ descriptions of autistic inertia align rather well with descriptions of catatonia of autism, particularly in terms of range of severity. The blogger's descriptions differ from the literature in that they discuss autistic inertia as common among autistic people and highly episodic in nature. In fact, the bloggers attribute explanatory power to autistic inertia when they discuss their tendency to demonstrate inconsistent skills and performance on tasks, an enigmatic autism trait that has been noted in the literature for many years (Bryan & Gast, 2000).

The concept of autistic burnout is not directly discussed in the literature, but it relates to certain concepts within the literature that are well documented. It has been established in the literature
that various social and sensory demands can be taxing for autistic people (Chmielewski, Wolff, Mückschel, Roessner & Beste, 2016; Deboth & Reynolds, 2017; Donnellan et al., 2013).

Interestingly, the bloggers identify an additional and even greater source of their exhaustion: the conscious inhibition of atypical movements for hours and days at a time. This is supported by two other qualitative studies that found university students who have Asperger’s report trying to “fit in” by managing their movements and behaviours and that this requires much of their energy (Knott & Taylor, 2014; Hastwell, Martin, Baron-Cohen, & Harding, 2012).

This link between conscious inhibition and burnout for autistic people may have another interesting implication. Baumeister, Tice & Vohs (2018) report on decades of research that explores the way conscious inhibition or self-control depletes a person’s reserve of energy, which could relate to the intense fatigue reported by bloggers. The bloggers describe this fatigue and report that it further reduces their ability to inhibit movements (leading to meltdowns). This reciprocal relationship between fatigue and inhibition has been demonstrated in the general population (Guo et al., 2018) but we are not aware of any discussions of this in the literature as it may relate to autistic behaviours.

For the bloggers, meltdowns are among the most challenging parts of living in an autistic body. Meltdowns have roots in arousal-regulation, but also relate to movement control. The bloggers stress that meltdowns are not planned nor engineered to “attain or avoid” in the behavioural sense. The autism literature does not directly discuss meltdowns but does discuss “irritability”: a term for the symptom cluster of aggression, self-injurious behaviour and “tantrums” (Lewis et al., 2018; Posey, Stigler, Erickson, & McDougle, 2008; Wink et al., 2018). The descriptions of meltdowns being out of the bloggers’ control align with work by Yang et al. (2017) who found distinct neural bases for behavioural expressions of “irritability”. Indirectly, this is also supported by findings that “irritability” symptoms do not respond well to behavioural intervention (Anagnostou, 2018), since behavioural interventions are highly effective for acquisition or avoidance behaviours (Matson, Hattier, & Belva 2012).

This study drew on blogs as a data source and found them to be a rich source of description for understanding insider perspectives of autism. Blogs have been shown in the past to be an excellent source for rich data in research with other populations (Hookway, 2008). Our findings indicate that the format of blogs allows autistic people to communicate on topics of importance
to them (Hookway, 2008), and so is a good source for data in a study that aims to reflect insider priorities. Blogs seem to be well matched to autistic individuals’ communication skills since they allow for non-speaking forms of expression, at the times that work for them (e.g. when not facing burnout), in sensory and social environments that they can control and at the speed that they can manage, without the pressure of another person waiting for a real-time response (Brownlow & O’Dell, 2006; Davidson, 2008). It also allows for technological accommodations such as speech recognition and predictive text. While decreased social demands have been identified as a source of appeal to autistic online users, online expression may be attractive for additional reasons. Philosophers have discussed online communication as a disembodied mode of interaction and for this reason has held appeal for people who have physical disabilities, or issues with physical appearance (Bowker & Tuffin, 2003; Zhao, Grasmuck, & Martin, 2008). Perhaps it is this disembodiment that also makes online communication appealing to autistic people. In this milieu, they can interact with others without their unusual and uncontrolled movements getting in the way, spoiling how others see them.

4.6 Implications for Research

As seen in other studies (Pellicano et al., 2014a&b), topics identified as important by autistic people do not match the topics most frequently discussed within the autism literature. Specifically, the bloggers place great importance on phenomena pertaining to arousal-regulation and movement, some of which (such as swapped responses and burnout) are essentially unstudied (Anagnostou et al., 2014; Baumer & Spence, 2018). These are important areas of consideration for future study.

The bloggers’ descriptions of living in an autistic body frequently pertain to physical avolitional actions (or inaction) that obscure their intentions, interests and level of understanding to an observer. This has critical significance to autism research, since much of it takes the form of observational research (Amaral, 2011; Anagnostou et al., 2014; Hens, Peeters, & Dierickx, 2016; Poljac & Bekkering, 2012). When research is based on observation of behaviours, explanation of said behaviours relies on the researcher’s interpretation, which will reflect the researcher’s understanding of autism. The bloggers in this study explain their behaviours in ways that challenge the interpretations seen in dominant literature. This suggests that future research
aiming to explain autistic behaviours could benefit from less reliance on observation and more on experiential knowledge of autistic people themselves.

Our finding that autistic people are interested and able to contribute to research and its processes aligns with those of Pellicano and colleagues (2014a&b) and provides evidence to support the idea that it is time to incorporate autistic perspective into the evidence we use. These are critical considerations as we move forward in autism research. To neglect this would be to double-silence people who already have communication difficulties (Grover, 2004; Booth & Booth, 1996). Further, an increase in participatory action research is another important next step in research and is emerging in studies such as those by MacLeod, Allan, Lewis and Robertson (2018), Danker, Strnadova and Cumming (2016), and Crane, Adams, Harper, Welch and Pellicano (2018).

### 4.7 Limitations

There are limitations to this study and the application of its findings. Since this study used extant texts as the data source, we were not able to ask clarifying questions of the bloggers, which would have allowed for greater clarity as well as member checking. This study would have been enhanced by the involvement of autistic research collaborators for consultation on research question, study design, analysis and knowledge translation activities. This study did not employ the sort of research techniques that generate generalizable results, nor are these results ready to be used for intervention design. Finally, as with any online research, we cannot confirm the identities, locations, stories or diagnoses of the bloggers whose sites we sampled, which means there is a risk of sampling a website that gives information that is misleading.

### 4.8 Conclusions

This study supports a conceptualization of autism that sees embodiment, movement and arousal-regulation as important to autistic peoples’ every-day lives. Our findings give weight to the position that autistic insider perspectives can be accessed and should be leveraged for optimal research outcomes.
Chapter 5
From “Since” to “If”: Using blogs to explore an insider-informed framing of autism and its possible impact on autistic trajectories

This chapter has been prepared for submission to the journal Disability and Rehabilitation. It is a report on a study that sought to gain insider perspectives on autism by examining blogs written by autistic people. This manuscript will be submitted after final defence to allow an opportunity to include all feedback from dissertation examiners. I, Christie Welch, completed this work, under the guidance of Dr. H. Polatajko, Dr. P. Rigby, Dr. M. Fitch. And Dr. D. Cameron.
5 From “Since” to “If”: Using blogs to explore an insider-informed framing of autism and its possible impact on autistic trajectories

5.1 Introduction

In this study, we aimed to explore insiders’ perspectives of autism. We pursued the question, “What understanding of autism can be developed by examining insider understanding of autism?” To do this, we conducted an inductive thematic analysis of blogs written by autistic people. In this article, we present our findings and discuss them in relation to relevant academic literature as well as possible implications for research.

5.2 Background

In the current dominant framing of autism, it is seen as “a cluster of deficits in social cognition and instinct” (Verhoeff, 2013, p 454). Within this frame, the observable behaviours and characteristics of autism are understood to be the sequelae of diminished social awareness, social interest and social motivation (Carpenter, 2013; Verhoeff; Wolff, 2004). This frame has been built on decades of intense research, which has focused on biomedical issues, to the exclusion of research that explores the perspectives and explanations of autistic people. (Amaral, 2011; Pellicano et al., 2014a&b; Tager flusberg & Kasari, 2013).

Generally, research aimed at understanding the observable behaviours and characteristics of autism has taken the form of observational research (Verhoeff, 2015). The findings of the observational research studies which form the body of autism literature, are conveyed through the researchers’ interpretations of behaviours and characteristics observed, without inclusion of participants’ explanations of observed behaviours (Van Drenth, 2018). In the absence of insider

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2 In this article, we have chosen to use “identity first language” in recognition of the preferences stated by the informants in this study as well as recommendations made by autism self-advocates (Owren & Stenhammer, 2013)

3 In this article, we use the term “frame” for a set of ideas attached to a phenomenon (Shefrin & Statman, 2000). One phenomenon can have several different “frames” built around it according to different perspectives (Shefrin & Statman, 2000).
explanations of autism behaviours and characteristics, current framing is founded on theoretical explanations; the three most influential being Executive Dysfunction Theory, Weak Central Coherence Theory, and the Theory of Mind (TOM) hypothesis of autism (Rajendran & Mitchell, 2007).

The omission of insider perspective within autism research is based, at least in part, on perceived difficulties accessing the perspectives of autistic people, owing to autistic people’s difficulty with communication (Preece & Jordan, 2010; Verhoeff, 2013; Tager Flusberg & Kasari, 2013; Tager Flusberg et al., 2017). There are two advances making autism insider perspectives increasingly accessible today. The first, is the emergence of technology. Online communication has become a common and effective way for autistic people to engage in the sharing of ideas (Gillespie-Lynch et al., 2014), and is showing growing appeal for autistic people, including those who cannot speak verbally (Gillespie-Lynch et al., 2014; Nguyen et al., 2014). The second advancement making autism insider perspective more accessible is the emergence of the neurodiversity movement. The neurodiversity movement promotes autism as a natural variance in neurological functioning and advocates for rights of autistic people, which has empowered a growing number of autistic people to publicly voice their ideas and concerns (Jaarsma & Welin, 2012).

Blogs are online diaries that usually have entries posted in chronological order (Hookway, 2008). They have received growing recognition as an excellent data source for health research (Braun & Clarke, 2006; Hookway, 2008). Bloggers share experiences, perspectives and ideas, in ways that give detailed context, which promotes deeper understanding of phenomena (Charmaz, 2006).

In this study, we aimed to explore insider understanding of autism, to build a deeper understanding of autism. We pursued the question “What understanding of autism can be developed by examining insider understanding of autism?”.

5.3 Methods

This study drew upon a data corpus that was also used in a separate study. The two studies share data generation strategies as well as an over-arching objective of exploring insider perspectives. However, the two studies pursued separate lines of questioning and employed different analytic strategies. The findings from the alternate study (which used deductive thematic analysis to
develop concepts of embodied autism) are reported in a complementary paper (Welch, Polatajko, Rigby, Fitch, & Cameron, 2018a).

5.3.1 Approach

A descriptive qualitative approach was used to guide this study of insider perspective. Descriptive qualitative research examines experiences of life in a thorough and reflexive way (Bradshaw et al., 2017). In this approach, it is important to provide a careful account of events or experiences, with theorizing that stays “close to the surface” of participant descriptions and presents the meanings of events as stated by the participants (Sandelowski, 2000). We approached this research from positions as health care professionals (with backgrounds in occupational therapy and nursing) which influenced the objectives and the analytic lens in this research (e.g. we were especially sensitive to concepts and insights that may have the potential to inform effective and compassionate practices). We also approached the research with the assumption that autistic people have important perspectives that warrant understanding.

5.3.2 Ethical considerations

While the use of extant texts such as blogs can be seen as a “minimally invasive” way of doing research, careful thought to ethics must be applied (Zimmer, 2010). We deemed these blogs to be fully and clearly “in the public domain” based on two characteristics that Willis (2018) identifies as important in online research. The first characteristic is how technically accessible the platform is, and therefore blogs were only included if they did not require passwords and if they were linked via the blog hub “Actually Autistic” (Actually Autistic, 2018), which seeks permission of bloggers prior to listing. The second important characteristic specified by Willis (2018) is the intended purpose of the platform as indicated by the platform users. Blogs were only included in this study if they did not have “members” only or “friends only” statements on the homepage. Additionally, we found that most blogs explicitly stated that the purpose of the blog is to educate other people about autism. Based on this, we determined that the blogs we sampled are intended by the bloggers to be used for public consumption. The decision to view blogs as public material has important consequences with respect to matters of confidentiality and anonymity (Roberts & Sipes, 2018). This assignation frames the bloggers as “authors” rather than “participants” (Roberts & Sipes), which evokes copyright considerations, requiring that we properly cite sources of the texts. Citation of the blogs eliminates the option of anonymizing the data, which is
often a preferred way to proceed (Roberts & Sipes, 2018). In this article, we reference the blogs using APA format, which means the blog’s author is identified by name or pseudonym if provided. If no name or pseudonym is provided, the blog title is used. This study received ethical approval from the Health Sciences Research Ethics Board at the University of Toronto.

5.3.3 Data and Data Generation

5.3.3.1 Description of Data Source: Blogs

Due to the communication challenges that autistic people experience, we sought a data source that leverages the communication strengths of autistic people. Online communication is appealing to autistic people, as it allows them to communicate at the times and places of their choosing, which allows them to minimize sensory, social and pacing demands (Gillespie-Lynch et al., 2014; Nguyen et al., 2014). Based on these characteristics, as well as the availability and suitability of blogs as discussed above, we chose blogs as our data source.

The term “blog” is short for “web log” and it refers to a series of electronic journal entries that are posted online, with the most recent post showing first and previous entries chronicled (Hookway, 2008). They are usually written by a single author, though sometimes they are shared by multiple authors (Hookway). Blogs often convey a strong sense of the author’s personality, passions, and point of view, and while they have some similarities to diaries, they are intended for a public audience (Nardi, Schiano, Gumbrecht, & Swartz, 2004). This means that while blogs tend to be personal, they can also be quite political and sometimes become a public forum for discussion (Nardi et al., 2004). The blogs sampled in this study showed diversity in tone (from serious to light-hearted) and focus (from autism-specific to daily life including friends, family, work and hobbies).

In this study, blogs were included for data extraction if they were written in English, by a person of any gender, culture or geographic location, who self identifies anywhere on the autism spectrum. Additionally, the blogs needed to “speak to a public audience” as indicated with either an explicit declaration on the home page, or the absence of a “members / friends only” statement or password requirement. We excluded blogs written by allies such as parents, clinicians or scholars, if they did not personally identify as being on the autism spectrum. A table listing all
the blogs sampled and their web addresses is provided in Appendix A. Figure 5-1 below depicts demographic information of the 40 blogs sampled.

**Figure 5-1 Blog demographics**

### Location

- **Unspecified**: 19 blogs
- **U.K.**: 1 blog
- **Netherlands**: 1 blog
- **Australia**: 1 blog
- **U.S.**: 14 blogs
- **Canada**: 4 blogs

### Gender

- **Unspecified**: 5 blogs
- **Non Binary**: 6 blogs
- **Male**: 12 blogs
- **Female**: 17 blogs

### Communication

- **Verbal**: 31 blogs
- **Typing**: 9 blogs

#### 5.3.3.2 Data generation

Since online methods of research are new relative to other forms of research, and since the online environment is always changing, the literature offers scant methodological guidelines for researchers (Hookway, 2008). It was therefore necessary for us to develop guidelines for the
data generation in this study. To do this, we sought out examples in the literature of studies using blogs (see Hookway) and methods articles specific to conducting online research and using blogs as data (Hookway; Prescott, Gray, Smith, & McDonagh, 2015; Rooke & Hambly Odame, 2013).

We generated data through a time-bound period of “blog trawling”. “Blog trawling” is Hookway’s (2008) term for searching blogs for content relevant to the phenomenon of study. Blog trawling involves searching blog sites, recording information in a descriptive documentation chart and “scraping” (cutting and pasting select content) from the sites. Each site visited was catalogued in a descriptive documentation chart which recorded demographic characteristics of the blogger (if known), identified purpose of the blog (if provided), whether the site has ability to leave “comments”, the date the site was visited, and the topics of the three most recent posts.

Hookway (2008) identified the importance of setting clear search parameters and guidelines for blog trawling. Accordingly, we set a time limit of 40 hours for the trawling, while being willing to conduct additional trawling if needed. We used the blog hub (a curated site that serves as a blog directory or search engine) Actually Autistic (Actually Autistic, 2018) to locate blogs. For three of the forty blogs sampled, we “snowballed” from within a blog directly linked from Actually Autistic. Data was extracted or “scraped” (Roberts & Sipes, 2018) from the blogs using cut and paste functions, with selected text pasted into offline data storage. Blog content was scraped and added to the data corpus if it discussed the blogger’s personal understanding of what autism is or why he or she behaves in autistic ways. Throughout the trawling process, the first author used reflexive memoing to record responses to data, development of ideas and research decisions (Charmaz, 2006).

After 40 hours of trawling, the first author conducted an open read of the data generated and presented a summary to the research team. We found the data set offered rich descriptions of varied phenomena, sufficient for two separate studies (as discussed above). At this point, we decided to begin analysis while remaining open to the possibility of additional data generation or data exclusion, as recommended by Braun and Clarke (2006). Upon completing two rounds of coding, we were satisfied that the dataset could provide sufficient description and detail for the objectives of this study and no further data were generated.
5.3.3.3 Data Analysis

Our lens for analysis was shaped by our methodological approach: qualitative description. This type of approach values rich description of informant accounts over a highly abstract interpretation of participant accounts (Bradshaw et al., 2017). In qualitative description, rigorous analysis requires deep immersion and engagement with the data (Bradshaw et al). In this study, this took the form of multiple open reads, multiple rounds of coding, collating of codes followed by checking collated sets against the dataset for internal consistency and coherence, as recommended by Charmaz (2006). Overall structure for analytic strategies (iterative and recursive coding, collating, mapping, reviewing and creating clear themes) followed Braun and Clarke’s (2006) recommended process. Analytic memoing was an additional tool for immersion, engagement and reflexivity, which was conducted through all phases of research (Braun & Clarke; Charmaz).

5.3.3.3.1 Key points in the conceptual development process

This analysis was inductive in nature, with no a priori codes. As the analysis progressed, we took increasing interest in the bloggers’ descriptions of how they define and understand autism, as well as their perceptions of how other people define and understand autism. We noticed that the bloggers frequently contrasted their current experiences with the experiences they wished to have. They linked their current experiences backward to supports they received (or did not) and to the way other people understand and define autism. Some of the bloggers used the word “frame” for how autism is understood and defined. In the bloggers’ descriptions of their desired experiences, they linked the potential of these experiences to the provision of alternate supports and to changes in the way autism is defined, understood or framed. It was based on these observations of patterns in the data that our conceptual development took on two new terms. We began to think of these blogger-described chains of events (both current and desired) as trajectories. We also added the word “frame” to our own taxonomy and started thinking of definitions and understandings of autism as frames. In the final stages of analysis, we decided to apply an over-arching concept of trajectories to structure, collate, organize and then present the perspectives of the bloggers.
5.4 Findings

Through inductive thematic analysis, we generated themes pertaining to insider framing of autism, as well as outsider framing of autism, as perceived by the bloggers. To present the findings, we have assembled the narratives from the bloggers and presented them as trajectories. The current experiences described by the bloggers are presented here as their current trajectories. The bloggers also described their preferred futures, in which new framings and interventions (which are now informed by autistic people) have created better possible opportunities for them at school, work and in the community. We have assembled the narratives of favoured futures and present them as preferred possible trajectories. The bloggers argued that both trajectories start with how people think about (or frame) autism: they suggested that this framing impacts autism treatment and societal response, which in turn impacts health and participation outcomes. To reflect this, we have structured the bloggers’ current trajectories using the titles Since you think…. You do this…. and this has been my trajectory…. We have structured the bloggers’ preferred trajectories with the titles If you thought…. You might try…. And this might be my trajectory…. Figure 5-2 depicts the trajectory-based structure of these themes and subthemes.

Figure 5-2 Trajectory-based structure of themes and subthemes

<table>
<thead>
<tr>
<th>Since...</th>
<th>If...</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>You think</strong></td>
<td><strong>You thought</strong></td>
</tr>
<tr>
<td>• I am unintelligent</td>
<td>• I was intelligent</td>
</tr>
<tr>
<td>• I am uncaring</td>
<td>• I was caring</td>
</tr>
<tr>
<td>• Autism is in my mind</td>
<td>• Autism is in my body</td>
</tr>
<tr>
<td>• Autism is all bad</td>
<td>• Autism is good and bad</td>
</tr>
<tr>
<td><strong>You do this</strong></td>
<td><strong>You might try</strong></td>
</tr>
<tr>
<td>• Leave me out of research</td>
<td>• Doing research that includes me</td>
</tr>
<tr>
<td>• Not hear me</td>
<td>• Giving me a voice (whether I can talk or not)</td>
</tr>
<tr>
<td>• Use misinformation for “Misintervention”</td>
<td>• Changing your interventions</td>
</tr>
<tr>
<td>• Make me feel like an outsider</td>
<td>• Accepting me</td>
</tr>
<tr>
<td><strong>...And this has been my trajectory</strong></td>
<td><strong>... And this could be my trajectory</strong></td>
</tr>
<tr>
<td>• Research meant to help me doesn’t</td>
<td>• Research will meet my needs</td>
</tr>
<tr>
<td>• I go unheard</td>
<td>• I will meet my goals</td>
</tr>
<tr>
<td>• I have poor outcomes</td>
<td>• I will be accepted</td>
</tr>
</tbody>
</table>
5.5 Current Trajectory

The bloggers frequently discussed how they perceive autism to be understood by researchers, professionals and the public. They contrasted these understandings, theories and perceptions to their own framings of autism, including what they consider to be the most important issues they face, why they engage in certain behaviours, what their biggest barriers to function are and how these should be addressed. The bloggers made links from the framing of autism they experience around them to current courses of action in autism research and intervention, to societal attitudes toward autism and to their personal health and participation outcomes.

5.5.1 Since you think …

5.5.1.1 Since you think … I am unintelligent

Many bloggers wrote about frequently confronting assumptions that they are unintelligent, unaware and disconnected from their surroundings.

Many people believe autism describes a simple mind, and that someone like me has no understanding or awareness of my surroundings (Zurcher-Long, 2015)

The bloggers link this framing to assumptions that decreased verbal skills and atypical movement patterns (which the bloggers acknowledge presenting with) are equated with low intelligence.

Upon seeing us do moves like flapping, rocking, or moaning, they assume we are unintelligent… People assume that not talking means not intelligent. Kindly get that idea out of your mind. Besides being wrong, it is insulting. Frame your mind to consider that your assumptions about non-verbal autistics are wrong. Rethink possibilities for all autistics, giving humanity to all not just some that are called high functioning. (Roses are Red for Autism, 2014)
5.5.1.2 Since you think … I am uncaring

Many bloggers find they are surrounded by people who assume that since they have autism, they are void of concern for or interest in others. Sometimes they find this difficult to refute using their verbal skills.

*Others believe that I do not have feelings at all. How do you defend yourself against such accusations? Trying to convince those who believe I’m an empty shell is impossible. Adding to this is my inability to use spoken language as expected … does not help change the minds of those who believe me incompetent and without feelings.* (Zurcher-Long, 2015)

The bloggers feel that the assumption that they do not care for others impacts other peoples’ interpretation of their behaviours. The bloggers stress that this is extremely frustrating and dehumanizing.

*According to some theories we cannot recognize emotions, we cannot visually distinguish relatives and friends from other faces, or know right from wrong. Some have even declared that we even cannot recognize a human being from an object. That’s pretty bad, huh…* (Kedar, 2015)

5.5.1.3 Since you think … autism is in my mind

Bloggers wrote about academic theories that inform current framings of autism and note that these are focused on cognition, comprehension and autism theories such as Theory of Mind. In contrast to this, the bloggers themselves emphasize, embodied and motoric issues that impact their behaviour and functioning.

*If a person cannot speak, cannot control his hand to write, cannot control his facial muscles to express his feelings at will (hence the flat affect of autism), cannot gesture, and cannot hold a pencil to write, how can this person prove that he understands? Why is it commonly assumed that a person with these challenges has cognitive delay when everything I mentioned in the previous sentence can also be seen as an example of a motor issue?* (Kedar, 2015)
The bloggers expressed frustration over the absence of consideration for physical factors impacting their function and the insistence upon a social interpretation of autism characteristics.

There’s a tendency in autism research to view autistic people’s abilities in ways that other disabled people’s abilities are not so frequently viewed. Blind people can’t usually read facial expressions. Deaf people can’t always hear tone of voice. But people don’t assume that blind or deaf people lack theory of mind because there are elements of nonverbal communication they don’t understand due to sensory impairments. But that’s exactly what is done to autistic people over and over — there are things that we just plain can’t perceive for various physical reasons, and then those are used as evidence that we don’t even know other people have minds at all. (Baggs, 2016)

5.5.1.4 Since you think … autism is all bad

Bloggers wrote about there being a pervasive sense of “doom and gloom” surrounding autism that goes unchecked among clinicians, researchers and advocacy networks. They frequently point to language used in clinical, research and advocacy contexts, where autism is referred to as an “epidemic” or a “global health crisis”.

Imagine that part of your being, something that has colored the entirety of your existence is likened to a tragic disease. (Vrana, 2016)

The bloggers feel that this highly negative picture has impacted how people perceive and relate to them.

We still have a long way to go being understood and included in all aspects of community life. We have to do a lot better starting at the beginning of autistic lives. Parents need less fear from doctors and more tempered guidance about autism neurology. (Roses are Red for Autism, 2016)

5.5.2 You do this …

The bloggers discuss their perceptions of how dominant framing of autism has influenced practices within research, clinical, educational and advocacy and community contexts.
5.5.2.1 You do this … leave me out of research

Some bloggers link current research foci and practices to current thinking in autism. They write about suspecting that since they are perceived to have little understanding of their own minds as well as the minds of others, they cannot have insights that are helpful to autism research. The bloggers also express frustration with continued research and practices that do not engage autistic insiders, despite the increasing accessibility of their insights.

I have only met a rare few neuro-researchers and other autism specialists, representing the scientific study of autism, who consult with me for my insights. I have noticed that though more and more of us nonverbal autistic people can type now I have not seen an increase in scientists trying to meet us. My book was sent to many neuro-scientists when it was first published, but few answered, and none met me. The puzzling thing for me is why this is. (Kedar, 2014)

The bloggers wrote about the feeling that autism research is conducted in order to confirm theories already held in academic literature.

Assumptions about the limitations of autistic people carry over into research in ways that shocked me when I first discovered them. I once had a conversation with a researcher I really respected, someone who was trying to do right by autistic people and understand our emotional responses and the like. I asked her the following question: “I know you’ve talked to a lot of parents of autistic children. How many of them overall told you that their autistic child is the first person to pick up on emotional tension in their household?” I’ll never forget her response. It went something like this: “Oh wow. Actually? I think every single parent told me that. But until now, I had instantly put it out of my mind. ... I just forgot about what I was being told, assumed the parents were just mistaken, things like that.” She was a very intelligent researcher who was trying her best to get past her biases about the abilities of autistic people. And it took that question to start putting two and two together. (Baggs, 2016)
5.5.2.2 You do this … not hear me

Many bloggers discuss how framings of autistic people as unintelligent and uncaring have led to autistic people being left out of important conversations. They indicate concerned that the medical model has formed such a strong framing of autism, that it cannot be shifted.

   Because you view me this way, with your belief in the all-knowing medical system, is the reason I slave in this current place. The medical community is a powerful voice that has incredible influence on families trying to find answers to the autism puzzle... Having a voice leave hard questions for people to answer. People do not want to think that they have been wrong for so long, which makes it hard to really see me, and others like me. (Dillan Bremache guest blog on Kedar, 2012)

The bloggers' writings suggest that since the dominant framing of autism that the bloggers experience does not include intelligence, insight or interest, it follows that autistic people are not consulted in planning their own treatment or education plans.

   The assumption that people with severe autism all have impaired thinking has resulted in the underestimating of the true abilities of thousands of individuals, lack of adequate educational opportunities, isolation, loneliness, boredom, frustration, hopelessness, and a life of entrapment within one’s own body. This price is too high. (Kedar, 2015)

5.5.2.3 You do this … use misinformation to design “misintervention”

Bloggers frequently discuss frustrations with interventions and supports they have (and have not) received. They link some of their greatest frustrations with intervention to the framing of autism as something in their minds (not their bodies) and the interpretation that problems in function have a social or cognitive cause.

   My instructors took data regarding whether I pointed to the right card or not. They thought they were collecting data on my receptive understanding of language. They were not. I understood everything, as any other child my age would. The data they were collecting, though they did not know it, actually
measured my poor ability at that time to get my hand to touch with accuracy the card I wanted, and did not reflect an accurate measure of how much I understood. My mind might be screaming, “Touch tree! Don’t touch house!” and I would watch, like a spectator, as my hand went to the card my hand, not my brain, wanted. And down in the data book it would be marked that I had not yet mastered the concept of tree. (Kedar, 2015)

Many bloggers found that when they failed a task in therapy, that task remained a goal indefinitely, regardless of the usefulness of that goal. They describe that repeated experiences of this can lead to mounting frustration and despair.

Too many times I was asked to do the simplest things; gathering certain shapes, for example, being a common skill taught in such programs. But when I moved to sort, only autism controlled my hands. My mind could try all it wanted, but it was impossible. (Bremache, 2015)

5.5.2.4 You do this … make me feel like an outsider

The bloggers discuss how people’s assumptions regarding autism are demonstrated in social interactions.

When I was a child there was often an assumption amongst teachers and other people who one might have reasonably expected to notice something was amiss, that I was deliberately weird, deliberately unfriendly, deliberately made myself a target for bullies, deliberately set myself up to fail. (Letters from Aspergia, 2014)

These social interactions include being teased, ostracized and indirect / public statements about autism that the bloggers experience as othering.

I’m in college, in a psychology class, where the professor tells us that Autistic people don’t care about other people. We only see them as objects to get something from. (She knows I’m Autistic and she’s taught Autistic students before.) (A Deeper Country, 2018)
5.5.3 And this has been my trajectory …

Bloggers described the ways they have been impacted by current research, intervention and public perception. The trajectories they described have been a mix of triumph and tribulation, with those who are meeting their personal goals identifying themselves as the lucky ones.

5.5.3.1 This has been my trajectory … research meant to help me doesn’t

The bloggers expressed frustration with research foci to date, stating that it does not match their topics of importance or their objectives.

*I think the research tends to concentrate on the things about autism that are a problem for or seem weird to neurotypical folk, like stimming and differences in social interaction. Things that affect us deeply but don’t affect those around us – like sensory/motor stuff and inertia – get a lot less press.* (Sparrow, 2016)

The bloggers were also quite critical of autism research processes.

*The state of autism research is pretty uniformly terrible. There is good research out there, but most research is bad. The bad research includes some of the most popular research used to support the most popular theories about how autistic people think, and why.* (Baggs, 2016)

5.5.3.2 This has been my trajectory … I go unheard

Bloggers discussed frustrations with going unheard in multiple contexts. One primary context is research. The bloggers express rising frustration with this, as their participation becomes increasingly feasible, including for minimally verbal people.

*If I were a scientist researching autism, or a specialist treating autistic kids, or running a program for autistic students, and nonverbal autistic people who could communicate by typing began to emerge, I think I’d make an effort to meet them. I understand there are skeptics. I understand there is doubt, but I also know that ignoring things doesn’t change reality. I know that for those skeptics who attack as fake every autistic communicator who appears in the news, that it is also impossible for them to be certain of a person’s skills and abilities without seeing the person.* (Kedar, 2014)
The bloggers pointed out how going unheard has impacted the focus and impact of the interventions they receive.

> Until autistic people have a voice in this discussion, there will continue to be a large gap in what they prefer to use to help them communicate and what is being given or taught to them. The motto of disability groups worldwide is, “Nothing about us, without us.” The world and particularly the Department of Education would be wise to heed those words and act accordingly by including autistic people in their planning moving forward (Zurcher-Long, 2017)

The bloggers discussed how persistently going unheard has had pervasive impact on their lives.

> Unheard minds, again and again, lose so much hope since we are expected to amount to little more than silly trials of therapies meant to help handle our needs, instead of first believing in us more. (Dillan Bremache guest blog on Kedar, 2012)

5.5.3.3 This has been my trajectory … I have poor outcomes

Bloggers link limitations in supports and services to limitations in their own health and participation outcomes. They discuss personal goals that have not yet been met. These goals often center around daily living skills and employment.

> My avolition can result in a total standstill of daily living skills — not just a failure to socialize, but a failure to eat enough, drink enough, keep a job, any number of things. (Baggs, 2017)

Other personal goals not-yet-achieved relate to successful employment. The bloggers most often link their difficulties with employment to problems with arousal regulation. The bloggers describe periods of being anxious, overwhelmed and exhausted.

> I crashed out of secondary school twice during the course of my five years there. I dropped out of college by the end of my second year. I bailed on my first ever ‘proper’ job at a fast food restaurant after less than two months and about ten shifts, half of which I didn’t go to. I had to give up on my
volunteering position in a cafe after a few months and several missed days. (Autisticality, 2015)

5.5.3.4 This has been my trajectory … I am not accepted

One outcome the bloggers frequently discuss is that they feel socially excluded in multiple contexts.

*I started this blog primarily to write about my new understanding of myself as an autistic adult who was an autistic child but didn’t know it. That autistic child grew up, accomplished quite a lot of difficult things, but could never escape a pervasive feeling of difference and alienation.* (Eclectic Autistic, 2016)

The bloggers who have severe difficulty with verbal communication, describe a sense of isolation that was particularly severe during the time before they could write or type. Ido Kedar explains:

*Thousands of autistic people like me live life in isolation and loneliness, denied education, condemned to baby talk and high fives, and never able to express a thought. The price of assuming that nonverbal people with autism have impaired thinking is a high one to families and to people who live in solitary confinement within their own bodies. It is high time professionals rethought their theories.* (Kedar, 2014)

5.6 Preferred Trajectory

The bloggers propose alternative framings of autism that they feel would be more accurate and more positive. The bloggers predict that this insider-informed framing of autism could change public opinion, research practices and intervention practices and ultimately their health and participation outcomes. We have structured these themes according to trajectories once again, this time in terms of the bloggers preferred trajectories: If you thought… You might try… And this could be my trajectory…
5.6.1 If you thought …

5.6.1.1 If you thought … I was intelligent

The bloggers promote a new framing of autism in which autistic people are presumed intelligent. They stress that verbal expressive skills should not be confused with thinking skills.

*Especially damning are the assumptions that my intelligence is low because of my thwarted attempts to respond the way others expect; with verbal words. I can remember a time when a person said to Mom that I have a very low IQ of 40, and I wanted to scream, NO! But I couldn’t. It was horrible not to be able to defend myself… Sometimes it gets so bad you scream and cry. If everyone assumed intelligence we wouldn’t have to go through that.* (Roses are Red for Autism, 2015)

The bloggers also stress that their difficulties with movement control can give the appearance of decreased awareness and intelligence, but that these are evidence of motoric difficulties not cognitive difficulties. To quote Jacob from Anchor of Hope

*It is important universally that people know how intelligent I am because my body betrays me all the time. I love to be with many helpers doing hard work but my body will not cooperate with me and wants to automatically hand over the work to others. This frustrates me so much that I lose control. I am constantly fighting my body to do what I want it to do. This is why I hurt myself by hitting my chest and head so hard and loud. I want people to understand that I am trying my best to control myself; not giving in to my body which wants my destruction.* (Harbin, 2017)

5.6.1.2 If you thought … I was caring

The bloggers assert that they are sensitive and empathic people.

*Why be modest? No one else is going to say anything good about me once they know I’m Autistic. So I’ll admit that I’m a kind, caring person. It’s certainly the way I am most often described by people who don’t know I’m Autistic. As I leave a room I sometimes hear people exclaiming, ”She is so sweet!” I always*
**do my best to be kind and polite to everyone, I volunteer, and I've chosen to take care of other people for a living. (Forest, 2015)**

In fact, many bloggers describe experiences of being over-empathic, when they are so deeply impacted by another person’s emotions, it affects their own ability to cope.

*Imagine being told you can’t feel empathy, even though you feel people’s emotions so much it bleeds into you. (Vrana, 2016)*

### 5.6.1.3 If you thought … autism is in my body

The bloggers emphasize an embodied experience of autism. They describe issues with movement control, body awareness, coordination and sensory perception as having a significant impact on their daily functioning.

*Nevertheless, the person cannot necessarily demonstrate intact thinking due to the motor issues that block speaking, handwriting, gestures, facial expressions, initiating actions, and more. So, smart intact people may spend years, or even their whole lives, in a body that traps them behind weird movements and unreliable, inconsistent responses. More than that, neurological forces may affect the sensory system, making sounds too loud or visual stimulation overwhelming. The frustration is compounded by autism experts who dumb down learning because of their belief that autism is a language processing problem. (Kedar, 2015)*

The bloggers give embodied and movement-based explanations for autism characteristics that are traditionally framed as social.

*I have a theory that issues with proprioception - knowing which bit of your body's where and what it's doing - plays a much bigger role in autism than we give it credit for... Body Language 101 is the importance of mirroring your subject's posture or body language as a show of empathy and means of establishing connection. So if you have a clinical suckage at doing that very thing... maybe that's where some of the 'autistic people have no empathy' thing comes from... So if I'm not properly familiar with how my body feels and the*
shapes it makes as I go about my day... could that be why my body language sometimes sends off a very different emotion from the one I'm actually feeling? And why I sometimes can't properly pick up or respond to the shapes that others' bodies are making? (Letters from Aspergia, 2012)

5.6.1.4 If you thought … autism is good and bad

The bloggers present a picture of autism that has elements of joy, as well as pain. In the bloggers' framing, autism comes with talents as well as challenges.

Autism gives me an outlook on life that is unique, somewhat due to the fact that I am not constantly talking in response to everything going on. Most people are rather obsessed with themselves and their own opinions, and lack listening skills. A cacophony of talking accompanies most every gathering. Somehow, constant prattling on is comforting to neurotypicals [non-autistic people]. They conceal their inner insecurities by never allowing a break in conversation. Meanwhile, because autism apraxia doesn’t allow me to speak, I can listen to all and carefully consider all perspectives. This gives me a great advantage in life, I believe. There is not the expectation on me to come up with the right responses immediately. So, I am able to take time to assimilate what I learn through listening. This is by far the best way for me to learn. Autism really is a pleasant listening life. There is so much richness to being a captive audience to the eminent orchestra of life all around me. (Roses are Red for Autism, 2016)

Sometimes framing autism more positively is a simple as changing vocabulary.

So what are 'special interests?' These are what you have when you mix a deep passion for a topic along with extreme attention to detail. So, here's why I like 'seeing past stereotypes' but I don't like 'seeing past disability'. My accomplishments are not made 'despite' 'my autism'- my accomplishments are the result of hard work and my way of thinking and processing the world, which is very much impacted by being autistic. (Vrana, 2016)
5.6.2 You might try …

The bloggers make many suggestions for how people can enact new thinking on autism through alternative courses of action in research, treatment and community support.

5.6.2.1 You might try … doing research that includes and is informed by me

Many bloggers discuss how research might be approached differently if researchers think about autism differently. The primary impact they predict is that autism research will be informed by autistic people. They look forward to research that draws on their experiential expertise.

*I believe our explanations for our symptoms are important in informing researchers in where to look for answers and how to better educate us...So many of us now type without any tactile support. Many of us are eager to collaborate and guide research ideas, but only a rare few researchers ask. If I were a scientist researching autism, or a specialist treating autistic kids, or running a program for autistic students, and nonverbal autistic people who could communicate by typing began to emerge, I think I’d make an effort to meet them. I understand there are skeptics. I understand there is doubt, but I also know that ignoring things doesn’t change reality.* (Kedar, 2014)

The bloggers also describe looking forward to collaborating on research design.

*By the way, I did end up describing to her, in detail, an experiment she could do that would test the abilities of autistic people to read certain emotions in other human beings, without requiring the autistic person to ever have to use or understand language throughout any of the experiment. It made use of technology and techniques already available to the research lab in question. And she told me that it was a very good research design. I hope that she will one day use it, because I want to see if I’m right in what I guess about this situation.* (Baggs, 2016)
5.6.2.2  You might try … giving me a voice (whether I can talk or not)

Many bloggers predict that if thinking begins to change about autism, more people with autism will be “given a voice” in multiple senses of the phrase: autistic people with low verbal skills will have better access to communication support and autistic input will be sought for decisions impacting, individual treatment, research and policy

_There are so many of us and it’s time to listen to our message, and include us in our own therapies and learning paths. It’s time to get to the next phase of treatment._ (Dillan Bremache guest blog on Kedar, 2012)

The bloggers predict that being given a voice will have a reciprocal affect and further improve how people conceptualize autism.

_Let’s listen to people with autism who can communicate to be partners, guides, teachers, role models and proof that though we may look or act autistic because of having autism, we are fully human, fully intelligent and deserving of peoples’ respect._ (Vrana, 2016)

5.6.2.3  You might try … changing your interventions

Bloggers predict that if predominant thinking on autism shifts to match their own thinking, interventions will change in a number of ways. One such way would be a greater focus on movement and physical control.

_I sincerely, altruistically, hope and pray that more autism pros like teachers and doctors will realize that autism causes major issues with getting the body to cooperate with the intentions of the brain to respond, but ability to comprehend is unaffected. This will make way for more appropriate help for autistics...Necessary accommodations for keeping on track at school include many things. Of primary importance are teachers who know you are smart, and paying attention, even when autism moves make it seem like you aren’t._ (Roses are Red for Autism, 2014)

The bloggers also predict that interventions would focus more on sensory processing and self-regulation.
Nevertheless, working on self-regulation and tolerating a wide variety of settings is much more essential than many other goals in autism treatment (Kedar, 2016)

If autism is reframed to align with insider framing, intervention will also have a greater focus on individual communication needs.

Please help dispel the practice of using only ABA type models to help autistics. Until there is the realization that the so called experts, unless autistic themselves, have no clue what is best for us, they must allow for that which we need to access communication (Zurcher-Long, 2017)

5.6.2.4 You might try … accepting me

The bloggers predict that if dominant thinking on autism shifts, they may experience greater acceptance from others.

I am also with those who say that beyond Autism Awareness, we need Autism Acceptance. It isn’t enough to be “aware” of autism if that awareness leads you to rail against it and treat it as a great burden on society that needs to be cured. Although I would hope that true awareness would not lead in this direction, acceptance is still another step beyond awareness. As Shannon Des Roches Rosa has written, “Awareness is passive. Acceptance is a choice.” (Eclectic Autistic, 2017)

For the bloggers, acceptance starts with openness, listening and kindness.

Showing kindness toward those who are different and embracing our imperfections as proof of our humanness is the remedy for fear. Love is a small word, but allow yourself to be consumed by the sensation and the world becomes a place of infinite possibility. I want my hard won words to give hope and inspire people to change how they think about autism and someone like me. (Zurcher-Long, 2015).
5.6.3 And this might be my trajectory …

The bloggers link their observations of the way people frame, research and support autism to their own health and participation outcomes.

5.6.3.1 This might be my trajectory … research will meet my needs

Often, the bloggers envision a future in which autism research is informed by autistic people and therefore focuses on the issues they assign as important, include autistic people as informants and collaborators and promotes more accurate perceptions of autism.

Never mind that the real “burden” of autism is the burden that society places on the different — a burden that often leads to anxiety, depression, and other co-occurring mental health issues. Research to lighten that burden would be welcome. Research could also alleviate symptoms of other co-occurring physical conditions common on the autism spectrum, such as epilepsy and gastro-intestinal problems. This sort of research could do a lot to benefit autistic people directly, rather than playing into a conception of autism as an epidemic, as some sort of blight on society. I would welcome research that would help me understand the details of my particular neurology, and that could, for example, help create strategies for managing sensory overload. Or we could have research into technologies to help autistic people who don’t communicate in standard ways — or whose sensory systems are perpetually on overload — to better have their needs met. Research like that, based on understanding the experience of autistic people, could also go a long way toward dragging the rest of society into a new understanding of both our strengths and our struggles — and maybe help create a place where we could fit in without trying to fit ourselves into the wrong mold. (Eclectic Autistic, 2017)

5.6.3.2 This might be my trajectory … I will be heard

The bloggers imagine a future in which their voices are heard in many settings. Their hope is that people in the community will listen to new ideas about autism and that this will improve opportunities, an example of this would be better education.
My hopes for 2016 are that we start getting autism right, and are willing to shed comfortable yet incorrect ideas about autism that keep us from getting the education and lives that we want and need. I look forward to the coming year being one for autistic voices being heard and listened to. (Roses are Red for Autism, 2015)

As our understanding of autism evolves and increases, I am optimistic that accessing an appropriate education won’t be as challenging for others who communicate differently. – (Samuel Capozzi, guest blog on Kedar, 2016)

The bloggers predict a ripple effect in which autistic voices are heard and serve to help other autistic people.

I can finally speak for myself now. I can talk with a voice. A voice that is now being heard. An autistic voice that is being heard around the world in people’s own lives and in their own families. (Bremache, 2016)

5.6.3.3 This might be my trajectory … I will meet my goals

Many bloggers express optimism that their personal goals are possible in the context of new thinking, new research and new interventions in autism. They picture improved health and participation outcomes. Some of these outcomes relate academic success.

I am hoping my peers are accepting of my autistic idiosyncrasies and are patient with my noises. I look forward to all that high school has to offer. Attendance problems due to anxiety can hopefully be a thing of the past if concordant strategies for autism success are used. I want to be at school consistently to be a part of the class of 2018. (Roses are Red for Autism, 2014)

The bloggers’ goals include steady employment and making meaningful contributions to society.

My desire is to educate my community about my struggle and hope they will accept my constant efforts to be a productive and contributing citizen. I want to own my own business one day and have a family of my own. This will take a great deal of work on my part because I do not have a huge amount of control. (Harbin, 2017)
5.6.3.4  This might be my trajectory … I will be accepted

The bloggers describe a desired outcome of greater social acceptance. They envision a future society that welcomes varied ways of seeing the world and varied ways of moving one’s body (including atypical postures and stimulatory movements). They hope to have more and stronger social relationships.

When I was able to communicate people began to talk to me more regularly. I love being included even if I can’t join in easily. I am becoming better able to integrate but I have to keep working at it daily. It is helpful if society puts in the effort to include me too...Making friends is life-making by giving me other people to learn from and really care about. Life would be boring without people to hang out with. I am going to teach myself to be less shy so I can enjoy meaningful friendships. I like when I can talk with my friends. I love peaceful conversations. Beautiful, cool, autistic people make my life delightful. I have practice being social now. Making friends is now a possibility. I hope to be a good friend too. (Philip, guest blog on Love with Autism, 2017)

In their preferred trajectory, the bloggers don’t need to work so hard to “fit in”.

It's funny because people, um, professionals always talk about "social skills" and they frame social skills as being able to look like you’re normal, but I mean, what I would call my social skills have vastly improved now that I don’t care about that anymore because you know when you're not thinking about trying to make yourself look like you're normal, you really are much more interested in other people and you have a lot more energy to spare on just caring about other people and listening to what they have to say. (Forest, 2010)

The bloggers look forward to having more friends who are also autistic.

Speaking of the fall semester, I am also excited to say that I have been working on getting a Neurodiversity Club started at my school! We had a preliminary meeting back in June to gauge interest among students who identified as
5.7 Discussion

The 40 bloggers whose writings we sampled for this study offer an insider-informed way to frame autism and its observable characteristics. Within this framing, autism is an embodied experience with elements that are both very positive and very difficult. In this framing, autistic people are intelligent, caring and social and have the skills and motivation to inform research. In this framing, primary challenges of autism are linked to embodied issues such as movement and level of energy/arousal. The beginning of this discussion section considers each element of this insider-informed framing in the context of relevant academic literature. It then goes on to discuss implications for research as well as limitations of this study.

The framing offered by the bloggers in this study presents autistic people as intelligent. This intelligence is presented not only where it might be expected (as with highly verbal autistic people), but also within people who have difficulty expressing their intelligence verbally and who display atypical movements and behaviours. The bloggers acknowledge that atypical gait and posture, “stimming” and “meltdown” behaviours can give an outward appearance of decreased intelligence, however, they state clearly that these are embodied phenomena relating to movement control and regulation (maintaining a calm alert state) rather than intelligence. As the bloggers indicate, the academic literature presents a dominant framing of decreased intelligence, particularly among autistic people who are minimally verbal (Centers for Disease Control, 2014). However, the literature recognizes that intelligence is one of the most heterogenous aspects of people on the autism spectrum and can be difficult to assess in this population (Grondhuis et al., 2018; Munson et al., 2008). Further, it is interesting to note that normal and above normal intelligence in the presence of non-responsive bodies has been observed in other populations, opening for consideration the possibility that autistic people could be a population who experience this as well (Berninger & Gans, 1986; Graham, Owen, Weijer, & Naci, 2018). The findings from this study join the body of work which calls into question the feasibility of measuring intelligence and comprehension of autistic people through traditional I.Q tests, which are currently the only tools available (Munson et al., 2008; Tager-Flusberg & Kasasri, 2013; Tager-Flusberg et al., 2017; Welch et al., 2018).
The framing of autism offered by the bloggers portrays autistic people as caring and social people who understand and consider the viewpoints of others. This is relevant to the complex and nuanced literatures pertaining to Theory of Mind (TOM) and empathy. Theory of Mind is concerned with a person’s ability to hypothesize on the thinking, emotions, and intentions of others (Baron-Cohen et al., 1985). TOM is among the most researched concepts in autism and has been presented by some scholars as a unifying explanation for the observable characteristics of autism (Baron-Cohen et al., 1985; Rao et al., 2016). More recently, the literature has begun to present a more complex understanding of TOM and empathy in autistic people, including work by Baron Cohen and Wheelwright, (2004), who now suggest that the ability to empathize with other people may develop later or differently, rather than not at all. Additionally, researchers such as Smith (2009) have put forth the empathy imbalance hypothesis (EIH) of autism. The EIH of autism submits that people with autism have a deficit of cognitive empathy but a surfeit of emotional empathy (Smith, 2009). Empathy surfeit is a trend seen in research exploring first person autistic narratives (Gillespie-Lynch et al., 2014; Fletcher-Watson et al., 2018). Empirical evidence for the EIH is growing (Smith, 2009; Yang-Teng, Chenyi, Shih-Chuan, Jean, & Yawei, 2014) and is congruent with the narratives of the bloggers [Recall Vrana (2016) who feels other people’s emotions so strongly they “bleed” into her]. Additionally, whereas early academic autism literature asserted that autistic people are socially aloof (see Wing, 1997), increasingly, first person narratives within the qualitative literature reveal that many autistic people long for increased and improved social interaction (Brownlow, Bertilsdotter Rosqvist, & O'Dell, 2015; Hastwell et al., 2012; Vincent et al., 2017; Welch et al., 2018).

In the bloggers’ framing, autism is an embodied phenomenon. Autism impacts their ability to move the way they want to and is the root of many social and functional challenges. The bloggers link difficulties with movement to their difficulties speaking, using body language and looking “normal”. Autism also makes the bloggers prone to episodes of extreme over arousal and extreme fatigue, which lead to difficulties succeeding at school and work. Historically, atypical movements, poor verbal skills and tantrum like behaviours have been framed as indicators of decreased comprehension and limited social awareness or interest (Verhoeff, 2013). However, a small but growing body of literature supports movement control as plausible causes for these observable characteristics (Bertilsson et al., 2018; Srinivasan & Bhat, 2013; Donellan, Hill & Leary, 2013; Welch et al., 2018). In fact, some scholars, such as Fournier and colleagues, have
proposed that movement issues be considered a core feature of autism based on their systematic review of the literature (2010). An embodied framing of autism was seen in our previous study (Welch et al., 2018) and has been noted in other qualitative explorations of insider autism perspective (Bertilsson et al., 2018; Donnellan et al., 2013; Frauke, 2015).

In the blogger’s framing, autism has advantages as well as disadvantages. The bloggers acknowledge unique strengths that come with their autism; strengths that have brought them joy and triumph. The bloggers also discuss components of autism that are frustrating, painful and isolating. The bloggers perceive that autism is publicly portrayed as all “doom and gloom”, something that has been noted in studies examining public discourses on autism (Mann, 2018; Parsloe & Holton, 2018). Scholars have noted that the media tends to portray autism in extremely negative, and reductive ways that can be very stigmatizing for autistic people (Mann; Parsloe, & Holton). Just as the bloggers attribute both their successes (e.g. in academics, creative work, and becoming strong social activists) and their tribulations (e.g. anxiety and isolation) to their autism, so did autistic memoirists in our previous study (Welch et al., 2018). Similarly, in a 2018 study by Ward and Webster, autistic university students reported that their traits such as determination, perseverance and passion in their areas of academic interests (which they link to their autism), contributed their academic successes, but that autism was also a source of anxiety, depression and isolation.

An interesting pattern to note within the findings of this study, is that the founding tenets of the insider-informed framing (intelligence, caring, embodied, more positive) are both explicitly stated and overtly demonstrated in the bloggers’ writings. Not only do the bloggers explicitly challenge perceptions that they cannot be intelligent if they cannot sit still or speak eloquently, they challenge such notions by writing thoughtful and eloquent blog posts. In addition to directly refuting assertions that autistic people have diminished empathy and TOM, they write about the thoughts, feelings and concerns of other people with insight and compassion. The bloggers explicitly state that autism is in their bodies as much as it is in their minds. They also dedicate great portions of their blogs to discussions of movement difficulties and levels of arousal. The bloggers explicitly state that autism brings them joy and uniquely autistic gifts. Congruently, the bloggers write with joy and creativity about beautiful and satisfying parts of their lives.
When envisioning their preferred futures, the bloggers picture a cascading effect in which a new insider-informed framing of autism has led to decreased stigma, improved support services and better health and participation outcomes. The bloggers’ description of autism as highly stigmatized is mirrored in other studies with autistic adults (Knott, & Taylor, 2014; Vincent et al., 2017; Ward & Webster, 2018, Welch et al., 2018) and some scholars agree that this stigma can be linked to medical model views of autism on which much of public perception is founded (Shattuck et al., 2018; Szatmari, 2018). Frames are known to draw attention to certain elements of a condition, while excluding or under emphasizing other elements (Fox & Aranko, 2017). Frames have been shown to be powerful in healthcare because they provide rationale for implementing various courses of action and tend to have enduring influence on practice (Fox & Aranko). The bloggers’ suggestion that insider-informed research and services could improve health outcomes and decrease stigma is further supported by the trends seen in the field of mental health, which has undergone a similar transformation thanks to self-advocacy groups and the recovery movement which have increasingly fostered insider-informed research and services, to good effect (Davidson, 2016; Smart, Naider, Rigby, & King, 2018).

### 5.8 Implications for Research

Research outcomes are optimized when research reflects the insights and priorities of the intended service user population (Goodare & Lockwood, 1999; Krumholz, 2008; Whalley Hammell, 2013). Our findings support those of Pellicano, Dinsmore and Charman, (2014a&b) that the current foci of autism research do not match the priorities of autistic people. To date, autism research has had a primary focus on epidemiology, assessment and diagnosis (Anagnostou et al., 2014; Zwicker & Herbert Emery, 2014). The bloggers identify alternate priorities for research, specifically mental health, fatigue, movement, sensory overload and general understanding the experience of autistic people. Most of all, the bloggers are asking that researchers approach their study with openness to new ideas, rather than seeking confirmation of old theories. The bloggers emphasize that they are interested and able to inform research on every level, regardless of their level of verbal skills. This is a critical consideration for future research. Innovative strategies for accessing autistic insider perspective are increasingly being generated and implemented (for examples see Danker, Strnadova & Cumming, 2017; Hill et al., 2016; Satchwell & Davidge, 2018) as is participatory action research with autistic collaborators (for examples see Ostmeyer & Scarpa, 2012; Vincent et al., 2017). Among the least studied
phenomena touched on in this study are those related to movement control and other embodied elements of autism. This is an important area for future study, in need of well designed, insider-informed studies to generate evidence for intervention design.

5.9 Limitations

There are limitations to this study and the ways our findings can be applied. This study would have been strengthened by the involvement of autistic research collaborators for consultation on research question, study design, analysis and report writing. This study used extant texts as the data source, and so we were not able to ask clarifying questions of the bloggers. This is a limitation since reciprocal conversation with the bloggers would have allowed for more in-depth exploration of certain topics, as well as checking-in to confirm the bloggers’ intended meanings of certain phrases and descriptions. In this study, we did not use an approach that generates generalizable results and the perspectives in the blogs we sampled should not be considered representative of the perspectives of all autistic people. Also, these results are not ready to be used for intervention design, as they are still conceptual in nature. Finally, as with all online research, we cannot confirm the identities, diagnoses, locations, or stories of the bloggers whose sites we sampled, so there is a risk we took data from a website with misleading information. We understand that for some readers, the inclusion of writing by people who identify online as non-speaking, will call into question the authenticity of portions of the dataset. However, we feel that on balance, it is more ethical and scientifically valid to include perspectives of people who identify this way, at risk of including some misleading information, than to completely exclude all perspectives of people who identify this way.

5.10 Conclusion

This study has explored perspectives of autistic bloggers, with an interest in how their insider perspectives of autism can improve non-autistic peoples’ understanding of autism. The bloggers present a framing of autism that is more embodied, more positive, more caring and more intelligent than the current dominant framing of autism. The bloggers convincingly suggest that adoption of this new insider-informed framing could have a positive impact on their health and participation outcomes. This study has highlighted both the importance and the feasibility of seeking out and incorporating insider perspective in future autism research.
Chapter 6
Discussion

6 Discussion

6.1 Introduction
In this chapter, I will highlight the objectives of this body of work and then offer a synthesis of the key findings. Next, I will discuss the significance of this research from a rehabilitation perspective and discuss implications for practice and research. I follow this with a discussion of knowledge translation strategies for this body of work and the limitations of the research. Finally, I offer conclusions on the research and a personal reflection on the research process.

6.2 Research Objectives
In Chapter 1 of this dissertation, I presented a literature-based argument that there have been limitations in the scope of autism research, due to the exclusion of research examining insider perspectives (Pellicano et al., 2014a&b; Szatmari, 2018; Verhoeff, 2015). I also argued that this has contributed to a significant gap in our understanding of autism, particularly our understanding of its observable behaviours and characteristics (Amaral, 2011; Pellicano et al., 2014a&b; Verhoeff, 2015). The research presented in this dissertation aimed to begin to address this gap with an overarching objective of building deeper understanding of autism, especially its associated characteristics and behaviours, by examining the perspectives of people who have those characteristics and express those behaviours. I have pursued this overarching objective through three sequential studies, each with specific objectives. The first study used inductive thematic analysis of memoirs for an early exploration of insider perspective and identification of phenomena of interest. The second study used directed content analysis of blogs to pursue a deepened understanding of embodied autism, this time with a broader and more varied source of writings that had not been professionally edited (as the memoirs had been). In the third study, I used the same data corpus from study #2 and applied inductive thematic analysis to blog content to more closely examine insider framings of autism. Together, these studies contribute insiders' perspectives of autism, especially its observable behaviours, as they have brought to light important insider explanations that could ultimately serve to promote insider-informed understanding of autism.
6.3 Synthesis of Key Findings

Here I present four key findings from the studies in this dissertation. I have designated a finding as “key” if it had strong resonance across all the studies and if I interpret the concept to be a high priority of the memoirists and bloggers in these studies.

6.3.1 Finding #1 Autistic informants in this research frame autism in a way that is critically different from the dominant frame in the literature

Throughout the studies in this dissertation, the memoirists and bloggers were found to present their own framings of autism and their own explanations for their observable behaviours and autistic characteristics. The memoirists and the bloggers identified that their insider framings of autism stand in sharp contrast to the dominant framing of autism.

As discussed in Chapter 1, current framing of autism reflects three dominant theories: Weak Central Coherence Theory, Executive Dysfunction Theory and Theory of Mind (TOM) of autism (Rajendran & Mitchell, 2007). Respectively, these three theories explain the observable behaviours and characteristics of autism by linking it to: 1) over attention to detail and absence of gestalt processing, 2) difficulty with attention, working memory, mental flexibility, and self-control and 3) poor, absent or delayed ability to understand the perspectives of others (Rajendran & Mitchell, 2007).

The findings of the studies in this dissertation support, extend and refute each of these three theories in varying ways and degrees. None of these three theories are fully supported by the accounts of the memoirists and bloggers. With respect to WCCT, the memoirists in Study #1 describe difficulties with “scattershot memories” as well as difficulties attending to pertinent elements of the environment due to competing sensory demands, which lends support to WCCT, though only for some of the memoirists’ characteristics. With respect to Executive Dysfunction Theory (EDT), the memoirists and bloggers discuss at length their difficulties with self-control. This aligns well in some ways with EDT, except that the memoirists and bloggers describe self-control in a more motoric and embodied way than is usually seen in the executive function literature. With respect to TOM of autism, the bloggers and memoirists explicitly claim and overtly demonstrate insight into the perspectives of others and a capacity for empathy that is more aligned with the Empathy Imbalance Hypothesis (Smith, 2009). In contrast to the
explanations for autistic behaviours that are presented in these theories, the memoirists and bloggers explain their autistic behaviours as embodied challenges relating to movement and arousal regulation.

Overall, the insider-informed framing of autism presented in this research portrays autism as an embodied phenomenon which has positive and negative elements. This framing presents autistic people as intelligent and empathetic. It links autistic behaviours and characteristics to embodied difficulties relating to movement and arousal regulation. When this insider-informed framing is placed in context of the academic literature, some interesting challenges arise.

Most of the academic literature supports current dominant framing, which depicts autism as a negative or even “devastating” condition that leaves individuals socially aloof and void of empathy (McGuire, 2011; Verhoeff, 2013). The academic literature also explains observable autistic behaviours as sequelae of limited social awareness, understanding and interest (Verhoeff, 2013). However, this dominant framing is built on research that has not included insider perspective (Szatmari, 2018). As the body of insider-informed research grows, so does support for a framing of autism that is more embodied (Bertilsson et al., 2018), intelligent (Vincent et al., 2017) empathic (Bertilsson et al., 2018; Dziobek et al., 2008; Vincent et al., 2017), and positive (Parsloe & Holton, 2018). This growing body of literature also supports insider explanations of behaviours, namely embodied phenomena (Bertilsson et al., 2018; Donnellan et al., 2013; Robledo et al., 2012).

6.3.2 Finding #2 Autistic informants in these studies want to be heard

Throughout the studies in this research, the memoirists and bloggers consistently expressed desire to be heard in multiple forums, including research, policy, their own education and intervention plans as well as public discourse on autism. The bloggers’ and memoirists’ eagerness to join these conversations are consistent with other studies which have noted autistic people’s desire to have a voice in research (Pellicano et al., 2014a&b), policy (Parsloe & Holton, 2018; Pellicano et al., 2014a&b) education (Gillespie-Lynch et al., 2017; Vincent et al., 2017), other services (Cos, 2016) and public discourse on autism (Bagatell, 2010; Parsloe & Holton, 2018). This eagerness to be heard is reflected in a study by Vincent and colleagues (2017), which explored experiences and challenges of autistic students at a university in England. This study is an example of participatory action research with autistic collaborators who informed each stage
of the research process. The collaborators on this study felt immediate impacts of the knowledge generated and intended emancipatory effects (Vincent et al.). They expressed feelings of empowerment and hope based on their experience of finally “having a voice” (p. 312).

6.3.3 Finding #3 Autistic people’s outward presentation may sometimes be a poor indication of their understanding, interests and intentions

The memoirists and bloggers reported serious difficulties in using their bodies to demonstrate their awareness, understanding, interests and intentions to other people. This is because the movements of their bodies do not always match their intentions. Sometimes, when they wish to move, their bodies remain still. Sometimes, when they wish to remain still, their bodies move. Sometimes, when they wish to do or say something, their bodies execute a verbal or motor response that is completely different from what they had intended. The bloggers’ and memoirists’ descriptions of intention-action-mismatch (indeed, even their ability and inclination to consider these things and write about them) challenges current academic theories on autistic behaviour which assume autistic movements are intentional and reflect poor social understanding and interest (Donnellan et al., 2013; Verhoeff, 2013).

6.3.4 Finding #4 Autism is an embodied phenomenon

When explaining their autistic behaviours and barriers to function, the memoirists and bloggers placed strong emphasis on embodied phenomena such as movement and arousal regulation. Movement related difficulties included inhibition, initiation, coordination and swapped responses. Arousal regulation difficulties included autistic inertia, autistic burnout and autistic meltdowns. Underlying both categories of embodied challenges is a brain-body connection that is often too weak but is sometimes too strong. Weak brain-body connection leads to poor monitoring of actions and difficulty with movement control. Overly strong brain-body connection converts emotional experiences into physical experiences and can lead to acting out or shutting down.

The autism literature is largely silent on embodied issues of autism. However, while regulation issues remain largely unstudied, there is an emerging body of literature exploring movement issues in autism, with a growing number of scholars suggesting that movement issues may be a critical component of life with autism (Donnellan et al., 2013; Miyahara, 2013; Srinivasan & Bhat, 2013). Additionally, the emergence of insider-informed research is beginning to shed light
on embodied phenomena and its impact on participation and quality of life (Bertilsson et al., 2018).

6.4 Importance of this Research from a Rehabilitation Perspective

Rehabilitation researchers and professionals are committed to investigating, designing and implementing interventions that are client centered, effective and compassionate (Cardol, De Jong, & Ward, 2002). This starts with a solid understanding and well-informed framing of the potentially disabling phenomena people face. In the case of autism, rehabilitation research and practices are based on frames that reflect researcher interpretations of observed behaviours and characteristics, without insider explanations for what those observed behaviours mean, or how and why they happen (Bolte et al., 2018; Pellicano et al., 2014a; Shattuck et al., 2018; Szatmari, 2018). Now that more autistic people are sharing their insights using communication technologies (Gillespie-Lynch et al., 2014; Nguyen et al., 2014), autism science can widen its scope of inquiry and its base of evidence. This research has highlighted critical discrepancies between insider framing and dominant framing of autism, thus highlighting tremendous opportunity to explore new areas of research and eventually new avenues for intervention and support. This is extremely exciting since there are known deficiencies in current autism services as well as health and participation outcomes (Howlin & Magiati, 2017).

6.4.1 Implications for Practice

From a rehabilitation perspective, it is important to consider how research can lead toward improvements in practice (Cardol et al., 2002). The research in this thesis cannot directly inform specific intervention design, as further study is needed to conceptualize, design and test appropriate techniques (Fraser & Galinski, 2010). However, the research in this thesis does have the potential to make important contributions to practice by expanding the available academic literature to include insider perspective. Expanding evidence so that it includes insider perspective is known to have both practical and ethical benefits to practice (Tait & Lester, 2005). One such benefit is to stimulate critical thinking in clinicians and reduce risk of implementing practices based on faulty assumptions (Whalley Hammell, 2015).
The informants of this research attach importance to how clinicians think about or frame the people they work with and the conditions they have. They offer an insider-informed framing of autism that, if accepted by rehabilitation professionals, raises questions and considerations that are important to practice. For instance, this research calls into question the practice of using low verbal skills as a proxy indication of low language comprehension and intelligence. Since the informants in these studies suggest that their actions do not always match their intentions, clinicians may want to approach behavioural interpretation with extra caution. Finally, this research supports the importance of establishing communication systems for clients as early and as effectively as possible.

6.4.2 Implications for Research

By exploring insider framings of autism, this research has uncovered exciting opportunities for new lines of autism science inquiry. To work toward more effective framing of autism, future research can investigate dominant autism theories and their underlying hypotheses to see how they hold up when examined with the added insights of autistic informants. Additionally, research can pursue a new line of inquiry focused on embodied phenomena such as movement difficulties and arousal regulation. Once new theories are explored with collaboration from autistic insiders, these can be translated to intervention designs which are then tested and refined through a series of experimental studies (Fraser & Galinski, 2010).

These studies have highlighted the feasibility of accessing autistic insider perspective for research. In these studies, extant texts, which were generated using both low tech (e.g. pointing to a communication board while someone else typed) and high tech (e.g. typing with a predictive text program) “writing” methods, were shown to be useful for accessing autistic insider perspective. It is worth exploring and innovating additional data generation methods that leverage the communication strengths of autistic people and avoid or minimize the social, sensory and pacing demands of traditional interviews. Such innovations could have direct clinical applications as well, since augmented communication strategies could enhance assessment and collaboration with clients.
6.5 Knowledge Translation

Thoughtful knowledge translation (KT) strategies will be important to maximize the contributions of this research. Current plans in this regard include submissions to scholarly, peer-reviewed journals and conference presentations. Additionally, having witnessed the power of blogs, and the importance of online communication to autistic people, I plan to create a researcher blog that includes lay summaries of this research and that may serve to open dialogue between scholars, autistic people and their allies. Additional social media initiatives, such as an autism-insider-informed awareness Facebook campaign would open exciting future KT opportunities, once I am working with autistic collaborators.

6.6 Limitations

There are several limitations of the research within this thesis that impact the application of its findings. The datasets in these studies were generated using extant texts which has two major implications. The first implication is that the use of extant texts makes contextual positioning of the data more difficult, because as Ralph, Birks & Chapman (2014) point out, a researcher benefits from the sensory involvement, symbolic interaction and implicit understanding of context that is generated by interacting with informants. Strong contextual positioning helps the researcher and the readers understand the phenomena of interest and helps to highlight how context could impact research processes and interpretations (Ralph et al., 2014). The second implication of using extant texts is that I was unable to ask clarifying questions or engage in member checking. In qualitative description research, it is important to adhere to the meanings that informants ascribe to events. I have attempted to do this across the three studies, however, reflecting my interpretations back to the bloggers and memoirists could have made the findings more robust. This research has not benefited from collaboration with autistic people in the design, data generation, data analysis or report writing stages of the research, however there is opportunity for this in future knowledge translation initiatives.

6.7 Conclusions

The research in this thesis set out to deepen understanding of autism by exploring autistic insider perspectives. The research took the form of three studies, which were conducted using two datasets. Over the course of the studies, an insider-informed framing of autism and its
characteristic behaviours took shape. This insider-informed framing depicts autistic people as intelligent and caring. It links much of their observable autistic traits to embodied causes such as difficulties with movement coordination and control and difficulties maintaining an adaptive level of arousal. The work within this thesis highlights both the opportunity and the feasibility of insider-informed autism research.

6.8 Personal Reflection on the Research Process

This dissertation documents a series of studies designed to deepen understanding of autism. In a way, it is also a record of a personal transformation. The process of developing this thesis has been a form of self-discovery as much as any other kind of discovery. I originally approached my PhD studies feeling like I had a certain expertise pertaining to autism. My self-perceived expertise was called into question early on in my studies, when I came across an online news segment featuring Carly Fleischmann, a young woman who is autistic and nonverbal (YouTube, 2018). The segment showed video of her rocking, humming, screeching and repeatedly hitting a couch with her hand. Juxtaposed over this video was a narration of writings typed by Carly herself. The writings were eloquent and insightful and discussed being “trapped inside her body”. Because I was deeply immersed in and adherent to the dominant framing of autism, I was shocked to see that a young woman who has no verbal speech, who engages in such intense and frequent stimming behaviours and who exhibits tantrum-like behaviours, could generate such an articulate narrative. Carly truly defied my understanding of autism at that time. It suddenly became clear to me that Carly knew things about autism that I did not. This experience prompted a discussion with my research supervisor and led to a new direction in research, which was the beginning of the work captured in this thesis. Thus began a process of searching, reading, rereading, questioning, deconstructing and, ultimately unlearning about autism. As my committee members can attest, this process has led to more than one epistemological and ontological crisis for me. As I approach the end of this body of work, I can say that I am better for it: a better researcher, a better learner, a better clinician and a better autism ally.

I have developed a great respect for the experiential knowledge of autistic people and a deep gratitude towards those who share their stories and perspectives for the benefit of others. Through the writings of the informants in this research, I have seen the importance of conducting and reporting research with great caution and respect, because the ideas presented in this work, if
they have any influence at all, can have influence that is helpful or harmful or possibly both. I deeply hope that the work within this thesis makes contributions that are helpful to autistic people and I am eternally grateful for the support I have received in generating it.
References


### Appendix A: List of Blogs Sampled

<table>
<thead>
<tr>
<th>Blog Name</th>
<th>Web Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unstrange Minds</td>
<td><a href="http://unstrangemind.com/autistic-inertia-an-overview/">http://unstrangemind.com/autistic-inertia-an-overview/</a></td>
</tr>
<tr>
<td>Letters from Aspergia</td>
<td><a href="http://www.lettersfromaspergia.com/">http://www.lettersfromaspergia.com/</a></td>
</tr>
<tr>
<td>As Small as a World and as Large as Alone</td>
<td><a href="http://withasmoothroundstone.tumblr.com/search/body">http://withasmoothroundstone.tumblr.com/search/body</a></td>
</tr>
<tr>
<td>Autistic Hoya</td>
<td><a href="http://autistichoya.com/">http://autistichoya.com/</a></td>
</tr>
<tr>
<td>Autistic in South West Virginia</td>
<td><a href="https://autisticinswva.wordpress.com/contact">https://autisticinswva.wordpress.com/contact</a></td>
</tr>
<tr>
<td>Autistics Speaking Day</td>
<td><a href="http://autisticsspeakingday.blogspot.ca/">http://autisticsspeakingday.blogspot.ca/</a></td>
</tr>
<tr>
<td>Jordyn's Rocky Journey</td>
<td><a href="https://jordynsrookyjourney.wordpress.com">https://jordynsrookyjourney.wordpress.com</a></td>
</tr>
<tr>
<td>Ballastexistenz</td>
<td><a href="https://ballastexistenz.wordpress.com">https://ballastexistenz.wordpress.com</a></td>
</tr>
<tr>
<td>Anchor of Hope Foundation</td>
<td><a href="https://www.anchorofhopefoundation.org/">https://www.anchorofhopefoundation.org/</a></td>
</tr>
<tr>
<td>Ido in Autism Land</td>
<td><a href="http://idoinautismland.blogspot.ca">http://idoinautismland.blogspot.ca</a></td>
</tr>
<tr>
<td>Typing for Change</td>
<td><a href="https://typing4change.com">https://typing4change.com</a></td>
</tr>
<tr>
<td>Emma's Hope Book</td>
<td><a href="https://emmashopebook.com/2015/12/02/i-am-emma/">https://emmashopebook.com/2015/12/02/i-am-emma/</a></td>
</tr>
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<td>Autisticook</td>
<td><a href="https://autisticook.wordpress.com/">https://autisticook.wordpress.com/</a></td>
</tr>
<tr>
<td>Bunnyhopscotch</td>
<td><a href="https://bunnyhopscotch.wordpress.com">https://bunnyhopscotch.wordpress.com</a></td>
</tr>
<tr>
<td>Eclectic autistic</td>
<td><a href="https://eclecticautistic.wordpress.com">https://eclecticautistic.wordpress.com</a></td>
</tr>
<tr>
<td>Evil autie</td>
<td><a href="https://evilautie.org">https://evilautie.org</a></td>
</tr>
<tr>
<td>Gareeth</td>
<td><a href="https://gareeth.com">https://gareeth.com</a></td>
</tr>
<tr>
<td>Name</td>
<td>URL</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td>Gretchen Leary</td>
<td><a href="https://gretchenleary.wordpress.com">https://gretchenleary.wordpress.com</a></td>
</tr>
<tr>
<td>I'm Somewhere Else</td>
<td><a href="http://adeepeercountry.blogspot.ca">http://adeepeercountry.blogspot.ca</a></td>
</tr>
<tr>
<td>It's Bridget's Word</td>
<td><a href="https://itsbridgetsword.com/">https://itsbridgetsword.com/</a></td>
</tr>
<tr>
<td>Just Stimming</td>
<td><a href="https://juststimming.wordpress.com">https://juststimming.wordpress.com</a></td>
</tr>
<tr>
<td>Kyriolexy</td>
<td><a href="https://speakingon.wordpress.com">https://speakingon.wordpress.com</a></td>
</tr>
<tr>
<td>Life with Aspergers</td>
<td><a href="http://life-with-aspergers.blogspot.ca">http://life-with-aspergers.blogspot.ca</a></td>
</tr>
<tr>
<td>Married with Aspergers</td>
<td><a href="http://bjforshaw.blogspot.ca/">http://bjforshaw.blogspot.ca/</a></td>
</tr>
<tr>
<td>Mr. Asperger</td>
<td><a href="https://mrasperger.wordpress.com">https://mrasperger.wordpress.com</a></td>
</tr>
<tr>
<td>Tiny Grace Notes</td>
<td><a href="https://tinygracenotes.blogspot.ca">https://tinygracenotes.blogspot.ca</a></td>
</tr>
<tr>
<td>We are Like Your Child</td>
<td><a href="http://wearelikeyourchild.blogspot.ca">http://wearelikeyourchild.blogspot.ca</a></td>
</tr>
<tr>
<td>Yes That Too</td>
<td><a href="http://yestattoo.blogspot.ca/">http://yestattoo.blogspot.ca/</a></td>
</tr>
<tr>
<td>Riko's Blog: PDA and more</td>
<td><a href="https://dragonriko.wordpress.com">https://dragonriko.wordpress.com</a></td>
</tr>
<tr>
<td>Roses are Read for Autism</td>
<td><a href="https://rosesareredforautism.wordpress.com/about/">https://rosesareredforautism.wordpress.com/about/</a></td>
</tr>
<tr>
<td>Autisticality</td>
<td><a href="https://autisticality.com">https://autisticality.com</a></td>
</tr>
<tr>
<td>Olliebean</td>
<td><a href="https://ollibean.com/living-my-disabled-life/">https://ollibean.com/living-my-disabled-life/</a></td>
</tr>
<tr>
<td>Opinions Learned from Autism</td>
<td><a href="http://www.opinionslearnedfromrpmandautism.com/about-me/">http://www.opinionslearnedfromrpmandautism.com/about-me/</a></td>
</tr>
<tr>
<td>Pixie Perceptions</td>
<td><a href="http://pixiebluesky.blogspot.ca/">http://pixiebluesky.blogspot.ca/</a></td>
</tr>
<tr>
<td>Mule and Muse Productions</td>
<td><a href="http://muleandmuseproductions.com/videos/">http://muleandmuseproductions.com/videos/</a></td>
</tr>
<tr>
<td>The True Ben Kingston Blog</td>
<td><a href="http://thetruebenkingston.blogspot.ca">http://thetruebenkingston.blogspot.ca</a></td>
</tr>
<tr>
<td>Emma's Miracle Music</td>
<td><a href="http://emmasmiraclemusic.blogspot.ca/">http://emmasmiraclemusic.blogspot.ca/</a></td>
</tr>
<tr>
<td>------------------------------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td>Faith Hope Love Autism</td>
<td><a href="http://faithhopeloveautism.blogspot.ca/">http://faithhopeloveautism.blogspot.ca/</a></td>
</tr>
<tr>
<td>Sarah Stup</td>
<td><a href="http://sarahstup.com">http://sarahstup.com</a></td>
</tr>
</tbody>
</table>
**Appendix B: Initial Code Book**

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism gives me gifts you don’t have</td>
<td>Special talents or sources of joy that are unique to autism</td>
</tr>
<tr>
<td>I take in the world differently</td>
<td>Visual and auditory perception, sensory processing</td>
</tr>
<tr>
<td>I know my brain works differently</td>
<td>Attention, memory, executive function</td>
</tr>
<tr>
<td>I get so embarrassed</td>
<td>Feelings of embarrassment, humiliation, shame</td>
</tr>
<tr>
<td>I know how professionals see me</td>
<td>Interactions with professionals, things they do and say and the impression it gives regarding how the professionals see informant</td>
</tr>
<tr>
<td>I know my autism is hard on you</td>
<td>Impacts on families, friends, class mates etc.</td>
</tr>
<tr>
<td>I know other people think I’m dumb</td>
<td>Perceptions / assumptions of low intelligence, behaviours from others that indicate this, emotional responses to this</td>
</tr>
<tr>
<td>It is critical to be understood</td>
<td>Importance of communication and how this impacts life broadly</td>
</tr>
<tr>
<td>Experience</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>I feel detached from my body</td>
<td>Difficulty monitoring body, limbs, movements etc.</td>
</tr>
<tr>
<td>I can’t stop my body</td>
<td>Problem’s inhibiting unintended movements</td>
</tr>
<tr>
<td>I am helpless in my body</td>
<td>Feeling out of control and helpless due to problems with initiation and inhibition</td>
</tr>
<tr>
<td>I can’t start my body</td>
<td>Problem’s initiating intended movements</td>
</tr>
<tr>
<td>Emotions feel physical</td>
<td>Physical experiences of emotional reactions: bodily responses to triggers that are happy, sad, stressful, frightening etc.</td>
</tr>
</tbody>
</table>
## Appendix C: Final Code Book

<table>
<thead>
<tr>
<th>Moving differently</th>
<th>Awkward movements, clumsiness, atypical posture, atypical gait</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism hurts sometimes:</td>
<td>physically, emotionally, socially, exhaustion, costs</td>
</tr>
<tr>
<td>Strength in autism</td>
<td>joy, creativity, intense joy, empathy, skills, accomplishments, insights, connections with others</td>
</tr>
<tr>
<td>Intelligence:</td>
<td>Speak=IQ, assumed low intelligence (harms of this), implications for schooling and relationships</td>
</tr>
<tr>
<td>Communication:</td>
<td>importance, verbal vs. non verbal autism</td>
</tr>
<tr>
<td>Mis / perceptions of autism:</td>
<td>like autism research, but more geared toward general public than academics</td>
</tr>
<tr>
<td>Mis / perceptions of me:</td>
<td>misinterpret my actions: / misjudge me based on how I look and what my body does (more personal than above), inside &amp; out do not match</td>
</tr>
<tr>
<td>Impact on others:</td>
<td>bloggers discuss how their autism impacts family members and others in their proximity (e.g.classmates)</td>
</tr>
<tr>
<td>Coping:</td>
<td>daily strategies, life decisions (e.g. energy conservation)</td>
</tr>
<tr>
<td>Advocacy:</td>
<td>Importance of autistic voice, unheard minds (Dillan), public education, pushing back at researchers</td>
</tr>
<tr>
<td>Passing –</td>
<td>working to look “normal” often also relates to inhibition and the attached effort / exhaustion</td>
</tr>
<tr>
<td><strong>Definitions of autism:</strong></td>
<td>Explicit discussions of own versus clinical and academic</td>
</tr>
<tr>
<td>---------------------------</td>
<td>--------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Accomplishments:</strong></td>
<td>Achievements like academic, occupational, social and advocacy</td>
</tr>
<tr>
<td><strong>Goals:</strong></td>
<td>Future: school, career, family / social, advocacy</td>
</tr>
<tr>
<td><strong>Harm:</strong></td>
<td>Negative consequences caused by others and their perceptions caused by research, public misperception, parents, teachers, therapists</td>
</tr>
<tr>
<td><strong>Spectrum (?):</strong></td>
<td>Discussions about the trueness of this, heterogeneity of autistics, discussions of aspergers’, whether should be considered separate</td>
</tr>
<tr>
<td><strong>Divorce:</strong></td>
<td>Concept that people must divorce themselves from / old ideas of autism</td>
</tr>
<tr>
<td><strong>Autstronaut:</strong></td>
<td>Isolation felt by people with autism, secondary to / caused by most of the other codes, sometimes feeling Sub human</td>
</tr>
<tr>
<td><strong>Self-acceptance:</strong></td>
<td>Discussions of journey to self-acceptance, choosing your (internal) battles</td>
</tr>
<tr>
<td><strong>Pathologizing:</strong></td>
<td>E.g. hugging becomes “stimming”, persistence becomes perseverance</td>
</tr>
<tr>
<td><strong>Future of autism:</strong></td>
<td>Social acceptance and accommodation, improved understanding, outcomes of advocacy, switch to understanding embodied, increased opportunity</td>
</tr>
<tr>
<td>My future</td>
<td>independence, goals (more personal)</td>
</tr>
<tr>
<td>------------------------</td>
<td>-------------------------------------</td>
</tr>
<tr>
<td>Autistic community</td>
<td>feelings of connection, strength, divisions / classifications, support, Autistic identity</td>
</tr>
<tr>
<td>Special interests</td>
<td>the pros and cons, place in life</td>
</tr>
<tr>
<td>Cognitive/ executive function</td>
<td>how impacts daily life, often about inhibition and initiation as well,</td>
</tr>
<tr>
<td>Language</td>
<td>Identity first language, labels, autism = me, autistic identity Actually should switch this around – the vocabulary piece is secondary to identity piece</td>
</tr>
<tr>
<td>Autism overwhelming”, “autistic burnout”</td>
<td>– are these their own or relate to others? Accumulated fatigue leading to functional decline</td>
</tr>
<tr>
<td>Autism research</td>
<td>discussion of autism research, trends, frustrations, contradictions, bad theories, harmful messaging, including referencing specific articles, conscious academic resistance, “scientific un-query” academics’ active or passive disinterest in autistic voices, I am the expert</td>
</tr>
<tr>
<td>Autism theories</td>
<td>especially theory of mind, eye contact, and low empathy, paradox of these</td>
</tr>
<tr>
<td>Intelligence</td>
<td>speak=IQ, assumed low intelligence (harm of this), implications for schooling and relationships</td>
</tr>
<tr>
<td>Communication</td>
<td>importance, verbal vs. non verbal autism</td>
</tr>
<tr>
<td>Mis / perceptions of autism:</td>
<td>like autism research, but more geared toward general public than academics</td>
</tr>
<tr>
<td><strong>Mis / perceptions of me</strong></td>
<td>misinterpret my actions: / misjudge me based on how I look and what my body does (more personal than above), insideout</td>
</tr>
<tr>
<td>----------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Autistic Inertia</strong></td>
<td>Whenever term used, descriptions of fatigue (cumulative) Inhibition? Executive skill? Physical? Bloggers talk about different kinds, both physical and executive</td>
</tr>
<tr>
<td><strong>Control</strong></td>
<td>brain-body connection and, emotional, impulse, loss of control – meltdown,</td>
</tr>
<tr>
<td><strong>Brain-body connection</strong></td>
<td>Body monitoring, Initiation – starting movements (physical), Inhibition – stopping movements (physical), switcheroo, Trapped / prison of a “rude” body</td>
</tr>
<tr>
<td><strong>Sensory</strong></td>
<td>Joy, pain, navigating the sensory world</td>
</tr>
<tr>
<td><strong>Stimming</strong></td>
<td>the good the bad, the ugly, functional and limits of stimming</td>
</tr>
<tr>
<td><strong>Intervention</strong></td>
<td>likes, dislikes, ideas, limits <strong>Want from others</strong>: how the bloggers whish other people would treat them, address them, talk to them, guide them, support them, Need boundaries / limits guidance, accommodations</td>
</tr>
<tr>
<td><strong>Middle ground</strong></td>
<td>not eradicate, not untouched also vital – check Ido page 12 in research and theories or “deepest pain” in non-collated data</td>
</tr>
<tr>
<td><strong>Autism hurts sometimes</strong></td>
<td>physically, emotionally, socially, exhaustion, costs</td>
</tr>
<tr>
<td><strong>Strength in autism</strong></td>
<td>joy, creativity, intense joy, empathy, skills, accomplishments, insights, connections with others</td>
</tr>
<tr>
<td><strong>Impact on others</strong></td>
<td>bloggers discuss how their autism impacts family members and others in their proximity (e.g.classmates)</td>
</tr>
</tbody>
</table>