THE RETROSPECTIVE EXPERIENCES OF A MOTHER OF A CHILD WITH AUTISM

by

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ABSTRACT

This naturalistic study used qualitative research methodology to investigate the retrospective parenting experiences of a mother of a child with autism. The primary objective was to record and understand the experiences in the life of the participant, and to compare these with the themes in the literature on parental coping. Ethnographic methodologies of data collection and analysis were used to identify and analyze issues/themes that have shaped her life retrospectively. Data was collected for the case study through in-depth, semi structured interviews. Eleven consistent themes emerged from the interview data: (a) diagnosis, (b) encountering autism, (c) fruitless sacrifices, (d) day-to-day living/stress and coping, (e) getting adequate treatment, (f) mother as teacher, (g) hopes and fears, (h) social reactions, (i) the 'other' child, and (j) falling apart, (k) maturing as a parent. Based on data analysis three themes have emerged which has not been represented previously in the literature. These themes and the implications of having a child with autism on the participant's life are discussed.
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The purpose of this investigation is to explore the experiences of a mother of a child with autism, retrospectively. This study attempts to record and understand the effect of this handicapping condition on a mother's life, to identify and analyze issues/themes that have shaped her life and to form implications that could be learned from the participant's experiences. Looking at her life retrospectively may allow the participant to relive her experiences and put them in perspective. Also, this study examines how adequately the current literature has captured the characteristics of her experiences. In particular it investigates the stages, and characteristics of parents' adapting to a child with a severe disability.

The impact of a severe disability is never restricted to the individual with the disability. Members of the immediate and extended family are affected in various degrees. Numerous studies have documented the high level of stress experienced by parents of children with a severe disability (Byrne, & Cunningham, 1984; Singer, & Farkas, 1989). Some studies focused on specific dysfunctions, such as mental handicap (Flynt, & Wood, 1989; Minnes, 1988), and spina bifida (Kazak, & Marvin, 1984). Other studies compared two or more dysfunctions, such as autism and
Domt’s syndrome (Holroyd, & Mcarthur, 1979; Noh, Dumas, Wolf, and Fisman, 1989), or autism and language disorder (Cox, Rutter, Newman, & Bartok, 1975). These data suggest that parents of children with a severe disability experience increased stress in parenting with the increasing severity of the disability.

**Models of Family Stress**

Recently researchers have begun to examine the powerful effect of a child’s disability on parents, having in the past concentrated on the reverse (Konstatareas, & Hamatidis, 1991). Family systems theorists emphasize the powerful cross-influences of the family system on its members (Bell, 1979). Any minor change in any part of the family system is expected to resonate across its entirety and to demand adaptational maneuvers to bring about a new state of balance.

A model of family stress developed by Hill (1958) has provided a framework for conceptualizing family adaptations to stress. This model allows researchers to more effectively examine stress in families of a child with a severe disability. Hill proposed the ABCX model of family coping with versus experiencing crisis. In his model, a stressful event (the disability of a member of a family), A, is presumed to be responded to by the family’s stress meeting resources (material or psychological), B,
and to be influenced by the family members' definition of the meaning of the stressor event, C, before either coping or crisis, X, may result. Konstantareas and Hamatidis (1991) suggest that merging Hill's ABCX model with Bronfenbrenner's (1979) social ecology model allows us to view the various characteristics of the family system as an ongoing transaction. Bronfenbrenner proposed that researchers should move beyond the narrow confines of the family and take into account the broader framework (e.g., extended family, health care system, and educational agencies) within which the families exist and operate. The combination of the social ecology model with the ABCX model provides a framework of broader scope within which one can investigate comprehensively the path of families with a child with a severe disability. This framework will be used in the case study. Although the stress associated with the presence of a child with a disability is an important consideration, its impact on the family is likely to be related to the family members' cognitive appraisal of the stress (C in the ABCX model) and to the family's coping resources (B in the ABCX model) (Crnic, Friedrich, & Greenberg, 1983).
Coping

According to McCubbin, (1979) coping is seen as behaviours, cognitions or perceptions directed at the resolution or alleviation of potentially stressful life events. During these times, resources are managed by the family system in order to decrease vulnerability to stress.

Based on their literature review on life stress, Wolf et al, (1989) suggest that among many potentially threatening events and life circumstances, those characterized by their intensity, magnitude, duration, and unpredictability tend to constitute the most stressful situations. The intensity and magnitude of communication and behavioural problems of children with autism, together with the atypical and persistent care-giving demands they impose and the unpredictability of their prognoses, place their parents at high risk for stress (Bebko, Konstantareas, & Springer, 1987; Bristol, 1979; DeMyer, 1979; Holroyd, & McArthur, 1976; Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins, & Plienis, 1991; Robbins, Dunlap, & Plienis, 1991, Noh, Dumas, Wolf, & Fisman, 1989).

Given this high degree of risk for stress, it is important to look at how families with a child with autism cope, and to document the stages and the characteristics of these parents'
experiences in order to assess the adequacy of the current conceptual frameworks offered by the literature as well as to add to it.

Learning that their child is disabled is one of the most stressful events facing a family of a child with a severe disability (Wickler, 1981).

Having an infant with disability is often experienced by parents as the death of the expected normal, healthy child. (Saligman & Darling, 1989: 86.)

According to Saligman and Darling (1989), in this early phase these parents go through a series of adaptational stages, from denial of the event, to bargaining with fate, to anger against self or others, to depression and withdrawal, and at a much later period, to acceptance. Although the grieving process for parents begins when their child is very young, the amount of time a parent needs to go through these adaptational stages is extremely variable (Witcher, 1989). Some may take years to complete, others may need less time, and some may never finish the five stage process. Once parents reach the acceptance stage, the process of adjustment begins, and continues through each child's life cycle, begins. These stages are virtually identical with the five stages of the grieving process associated with death and dying (Kübler-Ross, 1969; Witcher, 1989). Grieving is an initial way of coping with a child’s severe disability, but parents use a variety of other coping strategies to adapt their lives to their child’s condition. This stage theory of adaptation will also be
considered in relation to the retrospective experiences of the mother in the case study to be reported here.

Harris et al., (1991) summarized the two major models of dealing with stress: instrumental and palliative strategies. Intervention based on each of the models have been developed to help the adaptation of families of children with autism. Instrumental strategies (i.e., parent education, information programs) focus on empowering parents to implement change in the person or the environment. Palliative strategies, such as self-help groups, enable parents to tolerate stress through internal mechanisms.

Robbins et al., (1991) looked at the outcomes of a family oriented training program on the level of stress experienced by mothers of preschool aged children with autism. The researchers found that family stress levels had a highly significant inverse relationship with the amount of progress demonstrated by the children participating in the training program. Results of Donovan's (1988) research investigating the coping strategies of mothers of adolescents with autism suggest that the larger the number of areas of functioning that are impaired, the more stressful the adolescent is on the family's life. Donovan concluded that formal services and programs are critical in successful maternal adaptation to a child with autism. Coping strategies identified by parents in other studies are spousal support, acceptance of the child, and reliance on a social network (Bristol, 1979; Fong et al.; 1993; Harris et al., 1991).

The dimensions of social support include instrumental
assistance, information provision, emotional empathy, and understanding. These can be provided on a number of levels, including intimate relationships, extended family networks, friendship and less formal neighborhood or community contacts (Byrne, & Cunningham, 1985). Hammer (1983) has presented a model which explains the nature of the association between social support and stressful life-events. Social networks are seen as providing feedback, which confirms behaviour and maintains performance, thereby contributing to psychological functioning and the maintenance of health. Bristol (1984) reported that families who are strongly committed to and very supportive of each other more easily accept and cope with the child with autism than do other affected families. The elements of such support include encouragement, assistance, feedback and hands-on help in the completion of daily tasks. Wolf et al., (1989) found that for mothers of a child with autism, the impact of parenting stress on depression was suppressed by the perception of social support. It is important to briefly discuss autism in order to better understand the effect of this disability on parents' life.

**Characteristics of autism that induce parental stress**

Autism is a pervasive developmental disorder, affecting language, social, emotional, and cognitive areas, that is usually diagnosed in late infancy or early childhood, often after the parents have experienced confusion about their child's abilities
and self-doubt regarding their parental competence. Autism is typically characterized by inconsistencies in development (i.e., variable cognitive functioning, severe communication delay, lack of interpersonal responsiveness, good motor coordination, extreme behavioural disturbance).

Strengths and weaknesses exhibited by children with autism evolve as developmental processes transform the behaviours involved. Some children with autism are highly verbal, while some say only a few words. It has been estimated that about half of the children diagnosed with autism never develop functional speech. With regard to the other half, their use of speech has been reported as largely echolalic or stereotypic at best (Layton, & Watson, 1995). Some exhibit unique behaviours such as hand flapping, while others do this less often. Some of the children do not resist physical contacts, while others prefer not to be touched (Frith, 1989). It is the severity of the problem, along with the number of associated symptoms, that form each child's diagnosis as autistic (Layton, & Watson, 1995).

Although autism displays itself in different ways in each affected individual, there are some peculiar hallmarks that most people with autism exhibit. They seem to move among people as one moves among pieces of furniture. Their faces have a blank expression and a distant look. Most people with autism are resistant to social change or disruption in daily routines and prefer to keep their world the same (Layton, & Watson, 1995).

Children with autism display unusual styles of social, communicative, and interpersonal relationships that seem to
follow a different path than the development path of normal children (Frith, 1989). Children with autism are often described as preferring to play and interact with objects rather than people.

**Social Attachment**

One of the main questions regarding people with autism is whether their social relationships are impaired because they do not understand social interaction or because they do not care about social interaction. In the past decade, researchers have been looking for evidence of social attachment behaviour in children with autism. These studies (Dissanayake and Crossley, 1996; Rogers, Ozonoff, Maslin-Cole, 1993; Rogers, Ozonoff, and Maslin-Cole, 1991; Sigman and Mundy, 1989) investigated whether children with autism show preferential social responses to their care givers rather than to other people and whether they demonstrate distinct reactions to separation from and reunion with the care giver. All of the studies found evidence for the existence of some level of attachment between children with autism and their care givers as the majority of the studied children directed more social behaviour to the care giver than to the stranger and increased this preferential behaviour after separation from the care giver. On the other hand, these children did not demonstrate even very early forms of shared social awareness, such as joint reference. They tended to play in stereotypic ways with objects and did not attempt to share those
objects with their care givers. Researchers (Rogers et al., 1993, 1991; Shapiro, Sherman, Calamari, & Koch, 1987,) did not find any relationship between severity of autism, measured by the Childhood Autism Rating Scale (CARS), and attachment security. These findings seem to suggest that the deficit in social relatedness in children with autism does not stem from their absolute inability to form positive social relationships with others. The major implication of these studies is that children with autism do form social attachment, even though their social behaviours are very different from normally developing children. This leads to an intriguing question: Is it possible that people with autism have a specific social deficit because they are unable to recognize others’ feelings and intentions?

**Theory of Mind**

Based on his observations of his patients, Kanner (1943) believed that most children with autism “have come into the world with innate inability to form the usual biologically provided affective contact with people.” (pg. 250.)

People with autism are noted for their indifference to other people’s distress, their inability to offer comfort, even to receive comfort themselves. This lack of empathy can be explained by the growing experimental evidence that most children with autism are impaired in their attentiveness to and discrimination and understanding of even the most simple and basic emotions and their expressions (Frith, 1989; Hobson, 1991). The possibility
that children with autism lack a theory of mind has been suggested on the basis of their peculiar inability to relate to and communicate with others in a predictable way in addition to a weakness of central thought processing (Frith, 1989; Hobson, 1991). Premack and Woodruff (1978) defined the theory of mind as follows:

In saying that an individual has a theory of mind, we mean that the individual imputes mental states to himself and others... A system of inferences, of this kind is properly viewed as a theory, first because such states are directly observable, and second, because the system can be used to make predictions, specifically about the behaviour of other organisms (p 515).

In the area of communication, the inability to recognize persons as having mental life might explain why people with autism rarely establish eye contact. They do not use the language of eyes to communicate as they are unaware of other minds. This lack of awareness of other minds, the theory claims, leads to their inability to adjust their discourse according to interpersonal contexts, particularly with reference to the needs, interests, and knowledge of other people.

In the realm of cognitive function, it has been concluded that children with autism suffer from a central deficiency in the processing of incoming and outgoing information (Hermelin, 1976). This can be explained by these children’s lack of ability to grasp how other people can dissemble information from reality. This in turn leads to rigid and concrete thinking (Hobson, 1991).
In the social sphere, the impairment of the development of theory of mind prevents people with autism from forming intimate relationships as they are unable to preconceptualize personal relations and understand others' emotions (Shapiro & Hertzig, 1991). The lack of interpersonal responsiveness is one of the many sources of parental stress (Hoppes & Harris, 1990). Although their findings show that mothers of children with autism do perceive their children as demonstrating some attachment and affection toward them, the attachment and responsiveness to them is not as strong as they would hope.

The ability to relate to the mind of others is a central component in our understanding of what makes people human. People with autism seem to follow a narrow path without any regards to the outside world (Frith, 1989). That is partially why it is so challenging for parents and for society to relate to and accept people with autism. This in turn contributes to the overall stress experienced by parents of children with autism. With this in mind, we can focus on the impact this disability has on the parents' life based on the literature on changes in parenting experiences from birth to adulthood.

**Parenting stress during the life cycles of a child with autism**

Autism is a disorder of development, which starts to manifest itself in early childhood. Since it is a disorder that affects all of mental development symptoms its manifestation will
change with age. Certain features will not become evident until later, others disappear with time. Along with numerous stress factors that affect a family of a child with autism on an ongoing basis, there are also added stressors that occur at various phases of the family life cycle. The concept of family life cycle depicts the transitions through which families move as their children grow up (Harris et al., 1991). For the family of a child with autism each of the developmental transitions of the life cycle may be intensified because of the special demands of the child's disability.

It will be now considered what the literature has indicated are characteristics of autism at different stages and the implications of these for changing stressors on parents. These themes will then be compared to the retrospective experiences of the mother in this study.

a) Early childhood

The normal appearance and early development of the child with autism allows parents to experience the birth and their child's early months as normal. The family is confronted with the disability only after the child gets older and does not develop the expected degree of emotional attachment, language development and begins to display unusual behavioural patterns. These factors usually prompt parents to look for a diagnosis. It appears that the interval of experiencing the child as normal, and all of the consequent reinforcing cognition and affect that accompany such
an experience make the acceptance of the diagnosis even more
difficult for parents of a child with autism than for families
who are faced with their child's disability from birth (Harris,
1984).

According to Holroyd & McArthur (1976) a child with autism
typically requires a vast amount of parental time and energy.
This drain on family resources creates a greater level of stress
for the family of a child with autism than for families of a
child with a mental handicap. These conclusions are reinforced by
Beckman's (1983) findings that handicapped infants who are less
socially responsive and have more difficult temperaments, pose
more care giving problems. Children with autism, who display more
repetitive behaviour, cause greater maternal stress than do other
handicapped infants.

At the end of early childhood, the transitional event of
beginning school may reintensify the sense of grief for the
parents of a child with autism as they are again confronted with
the difference between their child and other children.

**b) Latency**

While their normally developing peers are taking their first
independent step in the process of discovering the world, many
children with autism in their latency years require almost the
same amount of custodial care as they needed in their early
childhood. It presents an increasing burden for parents to attend
to their child's basic personal needs such as toileting and
dressing since it is not part of parenting for a normal
developing child in his/her middle childhood.

c) Adolescence

The discrepancy between their child's physical size and
behaviour becomes even more noticeable to parents with the onset
of adolescence. DeMyer (1979) reported that the sheer demands on
families do not diminish as the child with autism grows older
although the specific kinds of problems encountered may change.
Moreover, during adolescence the parenting role grows more
stressful than it was earlier. This is the time when parents are
usually confronted with their child's psychosexual development.
However, adolescents with autism cope with their psychosexual
development in ways that are not seen as appropriate or
acceptable by society. This leaves the parents with the
uncomfortable task of monitoring their child's sexual behaviour
on an ongoing basis. This might explain why Bristol (1984) and
Holroyd et al., (1975) suggest that parental stress for mothers
is greater with older as compared to younger children with
autism. Unfortunately it is often the case that there are fewer
resources available to families with adolescent children with
autism. However, this is the time when parents need enhanced
support systems as they begin to realize that their adolescent
child with autism will grow up to be an adult with autism. The
permanence of the child's disability and the implication of that
on their own lives can be a significant stressor for the family (Harris et al., 1991) Dudziak, (1986) suggests that during adolescence the problems faced by these mothers of children with autism often increased primarily due to lack of support services

**e) Adulthood**

By the time their child reaches adulthood most parents are ready to enjoy their post-parenting years. This is usually not a viable option for parents who live with a child with autism. Most adults with autism require extensive supervision and assistance in basic self-care. Aging parents have to face the reality that their physical ability to cope with these demands are declining and they need to plan for their child's future. This stage of the life cycle is almost as stressful for parents as the diagnosis was initially (Harris et al., 1991). Parents who have kept their children at home until this point have to face all the emotional consequences of separation from their adult aged child with autism as they contemplate alternatives for adult living, such as a placement in a group home.
Rationale for this Study

The majority of the reviewed studies have used quantitative research methods to explore the feelings and parenting experiences of mothers and fathers of children with autism. On the other hand, Dudziak (1986), and Fong et al. (1993) employed qualitative research methodology to examine the experience of living with a child with autism. Dudziak (1986) employed a longitudinal approach to follow her subjects, five mothers of children with autism from their child's birth to adolescence. The interview technique that was used to gather data was not specified. Issues identified by her study included the child's resistance to change, the child's destructive behaviour and temper tantrums, sibling's coping difficulties, as well as mothers' isolation. Dudziak suggested that having a child with autism has an impact on social patterns and family relationships.

In another qualitative case study, Fong et al., (1993) also focused on the parents of an adolescent with autism. They conducted an initial interview and a follow-up interview approximately 3-4 months later. The format of the initial interviews was open-ended. The interviews were audiotaped and transcribed. Follow-up interviews were conducted with each family to validate the themes. After analyzing the data of the parent interviews, six areas of concerns emerged: behavioural, social and communicational, family related concerns, education and related services, relationships with professionals, and
independence and future concerns.

It is important to mention the growing body of literature written by parents of children with autism. These first hand accounts (Greenfield, 1971; Hart, 1989; Maurice, 1993) provide valuable insight into the lives of these families.

Based on the above literature review, it appears that the experiences of families living with children with autism have been investigated using various research methods. To date, there are no studies looking at how the experiences of these families have changed over time.

This single case study is about the parenting experiences of a mother of a child with autism, retrospectively. In it, I attempt to compare and validate the social ecology model combined with the ABCX family stress model, the stages of grieving, the two major models of dealing with stress: instrumental and palliative strategies, as well as the family life cycle model. Also, I attempt to identify attributes of the participant’s personality and her coping skills which make her story unique. From this study we might gain a better understanding of the effect of this handicapping condition on a mother’s life, in particular the stages and characteristics of parents’ adapting to a child with a severe disability.
CHAPTER TWO

RESEARCH METHODOLOGY

This chapter describes the research methodology as it was proposed and the course it subsequently took as it developed and evolved. A description of the design, data collection and date analysis is included.

Qualitative research methods are often associated with the collection and analysis of written or spoken text or the direct observation of behaviour. Some of the defining characteristics of qualitative research are: a focus on interpretation rather than quantification, flexibility in the research process, an emphasis on subjectivity rather than objectivity and an orientation toward process rather than outcome (Cassel & Symon, 1994). Moreover, this approach not only recognizes the autonomy of the participant, but also recognizes the part that the researcher plays in the research. In that role, the researcher is a social being who has an impact on the behaviour of those studied. As Hammersley and Atkinson described it:

We are part of the social world we study... This is not a matter of methodological commitment, it is an existential fact. There is no way in which we can escape the social
world in order to study it; nor fortunately, is that necessary. We cannot avoid relying on 'common sense' knowledge nor, often, can we avoid having an effect on the social phenomena we study. (1983: 15)

That is especially true in the area of narrative naturalistic inquiry which becomes both the method and the eventual story of the participants as they reveal the phenomenon under investigation (Conelly & Clandinin, 1990).

Qualitative case study is characterized by the researcher spending substantial time on site, personally in contact, reflecting and revising meanings of what is going on (Stake, 1994). A case study is a concentrated inquiry into a single case and it draws attention to the question of what specifically can be learned from a single case. Narrative is a form of 'meaning making' that organizes human experiences into temporally meaningful episodes. As Polkinghorne stated it:

Narrative is the fundamental scheme for linking individual human actions and events into interrelated aspects of an understandable composite. (1988: 13)

In narrative work, researchers are engaged in interpretation in every phase of the work. Taking the data and weaving them into a coherent pattern is very complex. Discourse analysis is often employed to guide researchers through this very process. Discourse analysis places the focus on language as used in social texts, both written and spoken. Attention is given to the structure and organization of discourse (Marshall, 1994).

I took an ethnographic approach to data collection and
analysis. This approach allowed me to gain some insights into the phenomenon of the parenting experiences of a particular parent with a child with autism. In this study my interest rested on a number of key issues that I had formed from the literature and from my own experiences as teacher of students with autism, such as attachment, coping, grieving and stress. I felt from the beginning that these could be best recorded by entering the world of the participant in as unobtrusive manner as possible and by allowing her story to unfold. Data collected from the interviews provided a rich data base of the above mentioned key issues. Therefore I sought to validate those while working with the transcript as well as I attempted to identify new themes that might be unique, not mentioned in previous research. Data collected from the interviews were used to construct the narrative of the case study.

The Case

Identifying Participants

One of the goals of this study is to understand the retrospective experiences of parents of adolescent children with autism. Initially three parents whose children were 18 years old or older were approached to participate in my study. Two of those parents expressed a high level of interest in this project. The purpose of the study and the level of parental involvement was explained to each participant.
Each participant was assured that the identities of the children, parents, relatives and other care givers would not be revealed in any discussion of findings. To assure confidentiality pseudonyms are used in all reports. Colour coded files and binders were employed for documents related to the data.

Over the next three months only one case was followed since the information gathered from that case seemed to be sufficient to fulfil the purpose of this study which was to develop new insight into the experience of parenting a child with autism.

**The participant and the Setting**

Kathy is a single mother who lives alone in a small town north of a large city. One of her sons, Larry was diagnosed with autism at age four. Interview time and location was arranged at Kathy's convenience over the phone. All three interviews were conducted in her home after work hours. Kathy was informed of her confidentiality rights and her right to discontinue participation at any time. Before the first interview she signed a form consenting (See Appendix I) to participation and to the audio taping of the interviews.
Data Collection

Semi-Structured Interviews

The reason interviewing was chosen as a method to collect data for the study was because it promised to bring me closer to the retrospective experiences of the participant of the study. Interviews allow informants to choose the events that matter to them and put their own construction on them. Different type of interviews such as structured, unstructured and self-administered questionnaire are often employed to gather research date while conducting qualitative studies (Cohen & Manion, 1994; Denzin & Lincoln, 1994). Different types of interviews are suited to different types of situations.

Because one of the goals of this study is to record the retrospective experiences of a parent with a child with autism, semi-structured face-to-face interviews were used as the principle means of gathering information. Semi-structured interviews have partly originated from therapeutic fields. Unlike structured interviews, semi-structured interviews are dominated by the respondent who directs and sometimes initiates the course of the encounter. This type of interview could be described as a conversation between two people in which one of the participants is sharing their story. The other participant, the interviewer, listens carefully and empathetically, asks questions and takes notes if necessary. The interviewer's guidance should be minimal in order to allow the participant to tell the 'whole' story. It
is the interviewer's challenge to keep track of the seemingly endless range of possible events and stories and to be prepared to follow leads in many directions and hold them all in context as the work proceeds (Cohen & Manion, 1994).

In developing the protocol for the semi-structured interviews, I formulated questions to attempt to get to the heart of the participant's parenting and related personal experiences. However, not all questions from the protocol were asked as I allowed and encouraged the participant to initiate and direct the course of the encounter. Two initial interviews were conducted to gather information and a third one was performed to validate the findings of the initial data analysis. All interviews took between 2 hours and 2 hours and 30 minutes to complete. These interviews were audio-taped on standard audio cassettes. Verbatim transcripts were made of all audio-taped interviews.

**Memory Prompts**

Participant was asked to gather memory prompts such as baby books, and photographs before the interviews. This request was made in order to enhance the participant's memory and her ability to recollect stories relating to her child. Also, these memory prompts provided valuable visual information to the interviewer about the participant and her child's lives.
The Analysis of The Transcripts

The audio cassettes were transcribed verbatim using Microsoft Word. I then read all the transcripts and checked their accuracy with the tapes. After this initial overview the transcripts were read in their entirety in order to pick out recurrent patterns in the organization and content of the text. My aim was to isolate any examples of similarities differences, or variations in what was being said. In this study, a preliminary task entailed taking out any extracts where the participant talked about her parenting experiences, the way her relationship with her son evolved over time and the way her life has been effected by her son's handicap. This process was repeated several times. Each time extracts were placed under broad headings such as 'Diagnosis', 'Coping' or 'Maturing as a parent'. Eventually eleven dominant discourses (See Appendix II) were identified and are presented in the case study.

After the identification of the dominant discourses, I returned to the participant, Kathy for a final interview. During our last conversation, the final step of triangulation to assure the authenticity in the findings (Mathison, 1988) was done. The credibility of the qualitative methodology employed rested on the trustworthiness of the data (Bogdan & Lutfiyya, 1992; Lincoln & Guba, 1985). This final check could indicate whether my understandings, assumptions, and interpretations were accurate or
whether they altered Kathy's story. Kathy applauded the authenticity of my initial findings.

Q. I think we're done. Do you have anything else to add?

A. I think it's a really good outline. You have touched the things that are important to me. I think you've got a handle on how it is for me, how it was. Reading that outline, I think we really ... That the questions that you put to me ended up covering everything and they're very thorough and I cannot really think of anything that we didn't talk about. Practical things, emotional things, everything.

The goal of this last interview was to validate the initial findings by the participant and solicit feedback from her. The interview was audio-tape recorded and transcribed. Based on the participant's feedback the narrative was revised.

While analyzing the interviewee's discourse I describe my own understanding of the text, trying to remain faithful to the experiences of the interviewee and the way she herself formulated it. Relatively long segments of text are included in the case study to allow the reader to assess the researcher's interpretative conclusions. In terms of presentation, the use of ellipses (…) indicates that there is material omitted from the extract. Given the emphasis that discourse analysts place on working with contextualized utterances (Marshall, 1994), indication is given of the interviewer's comments or questions before and during the extract.

A researcher in reporting a case study must determine to
what extent confidentiality and privacy can be and must be protected while still preserving the relevant events, dynamics, and responses in a particular case. In the relatively small community of professionals and agencies working with children with autism, even disguising the identities of agencies and their employees may not be sufficient to protect participant privacy. Therefore pseudonyms of agencies, centres, hospitals, and professionals are used in the case study without altering essential characteristics of the settings.
Kathy and I already had a relationship as I had been Larry's teacher for a couple of years while Larry was attending a Treatment Centre. As a teacher, I always considered Kathy as a caring mother who had a very good understanding of her son's strength and weaknesses. Also, she gave the impression of a very open minded person who could express her ideas and feelings very well. I no longer work at this Treatment Centre. Kathy lives in an apartment in a cooperative in a small town. She works full time in an office. She has two sons; Peter and Larry. Peter, the elder son, moved out a couple of years ago, and Larry lives in a group home. Larry was diagnosed with autism at age four. Larry, who is 19 years old, has few practical skills and uses a limited number of signs to communicate.

Kathy is a great interviewee. She is very articulate and animated. Her personality is friendly and warm. During our conversations, we sat in a cozy spot in her living room and talked about her parenting experiences with Larry and the effects of Larry's handicap on her life.
As I learned from her, Kathy used to live in a middle size city with her husband. She had her first son, Peter, when she was 28 years old. Peter was born with a medical complication that was corrected by surgery soon after his birth. Six years later, Kathy's second son, Larry was born. His birth weight was very low (3 pounds 11 ounces) and Kathy had to wait for four weeks before she could take her newborn son home from the hospital. Larry was so tiny, Kathy felt he needed all the love she could give him. She carried him around in a papoose carrier on her chest and she was very happy with him. Larry was six month old when Kathy separated from her husband (later on they divorced) and she moved to a large city. Her apartment was located in a middle-class neighbourhood, and it was within walking distance of her parents' home. From then on, Kathy raised her two sons by herself with a lot of support from her parents.

**The discourse of “Diagnosis”**

For the first while Larry seemed to be doing just fine. Although his birth weight was very low, by one year of age he was at the right weight. He sat up at the right time, he walked at the right time. He was a very happy baby who showed attachment to people around him. The only abnormal behaviours were a lack of babbling sounds, a bouncing on his toes, and flapping of hands from early on.
Q. And you didn't think at that point that it was unusual?

A. Not unusual to worry about. Just. When you look at these things one at the time, it's nothing. So he's not talking when he's 2 years old. Well, a lot of people don't.

After his first birthday Larry began to change. He became distant and his face had a blank expression. It was a struggle to do anything with him. He didn't want to get dressed, he went into tantrums all the time and he always wanted to be left alone. All he wanted to do was to play with his blocks by himself. Kathy was watching this process with great uncertainty. She was trying to stay positive about Larry and not to put the wrong meaning to his behaviour. After a while she could no longer deny that something was wrong with Larry.

A. But he did reach that stage where you expect to see some things happening and nothing happened.

Q. And did you feel that it was a sudden withdrawal or it was a ...?

A. Looking back, I guess it was sudden. Because it happened in a short period of time, but it seemed to creep up on us and you know, between 18 months and two years and then at two years of age my mother and I were talking about him: 'Something is really wrong - but we don't know what it is...he seems happy, he's growing, he's walking, not talking but lots of kids don't' and we couldn't put, you know, it was hard to identify and we just decided we have to find out, something is wrong, we don't know what.

That is when Kathy and her Mom began their quest for Larry's
diagnosis. Most specialists told them that Larry was fine and he would grow up being normal. An audiologist diagnosed Larry deaf. Kathy argued about that diagnosis but to no avail.

A. And I said, you know, "He is not deaf." "Yes, he is deaf, he does not react to anything. He is deaf." So I said to her: Watch. I'll turn away, he cannot see me and I'd said: "Larry, there're cookies in Mommy's bag". And he went and got my bag and brought it to me. He is not deaf. No, he didn't react to anything there. We were in the same room and they had speakers all over and on would come a blast of a horn and I'd jump 10 feet (little laugh) and he didn't move.

This was Kathy's first encounter with professionals who can be very patronizing and do not consider parents as equal partners. Larry was diagnosed with autism around his fourth birthday. A psychiatrist explained to Kathy what autism was and what to look for. She felt that the description perfectly fit Larry's behaviour.

After the diagnosis was made, Kathy and her sons were able to access all kinds of special services, like a special preschool program, after school care, a support worker once a week, and a sibling workshop for Peter. Kathy felt that she had to fight to get the label 'autism' for her son.

A. Fighting for a label. Yes, it seems very strange to want to call your child, to have that handicap to put that name, but it's the only way you can help the child. Without that, he's at the back of the classroom where there's no help. You know, he needed that. We needed someone to say; yes, he has this problem and he needs to go to a special preschool, he needs therapy, he needs this or that. And so we were hoping to get a definite diagnosis for that reason. And just because,
you know, once you have an answer, then you can begin to deal with it. When you have just a lot of uncertainty, how are you suppose to deal with that. Not knowing anything. And Larry was a confusing little kid, because some days he was fine. And you'd think; 'Oh, whatever it was it's getting better.' And that he'd be really bad for a week. It was just up and down and up and down until we finally got the diagnosis, then we knew why he was up and down all the time. And we knew, what his problem was.

After the diagnosis, Kathy's mother, Barbara started to search for a reason behind Larry's problems. She wanted to know exactly why and how this had happened. Barbara was thinking of all the things that could have gone wrong during Kathy's pregnancy. In this process, without recognizing it, she was blaming Kathy. Kathy was able to discuss this with her Mom and asked her to stop searching for possible mistakes that might have been done during her pregnancy. On the other hand, on a certain level, Kathy also wanted to know the reason. However, she felt that knowing how it had happened would not have changed the outcome. The way Kathy talks about the fact that Larry is autistic shows how well she accepts him and that she as a mother uses her energy to care for her child rather then dwelling on his handicap.

Q. Have you ever looked for a reason, have you ever tried to blame anybody for him being autistic?

A. Not any persons. I know what happened. The doctor explained it to me what went wrong during the pregnancy. (Kathy had a partial separation of the placenta at five month.) I really don't think that anyone could have done anything at all. It just happened. Accidents happen. And I don't think you can
lay blame anywhere. Even when he was born, no one took extravagant measures to keep him alive. He was fed and if he lived he lived. They weren't doing wonderful medical things to make a child survive who shouldn't survive. He was little and he fought and he lived. So I assume that he should be here. And he should be exactly who he is. Because that's the way it happened naturally. Nobody did anything to make it any different. It just happened that way, the natural flow of things. So you have to accept it as just the part of life. You cannot say: 'Well that doctor saved him and he shouldn't have', or anything like that. It's not a person or, nobody did anything to cause it.

Like any other parent who has a child with autism, Kathy was confronted with the 'refrigerator mother' theory, that children with autism are made autistic by mothers who do not love them. However, she always knew that this theory did not apply to their situation. Larry got all kinds of loving from her, from his brother and from her parents. She feels confident that she has given as much love to Larry as he needed, sometimes even more as Larry was trying to avoid any affection for a long period of time. It was really moving to hear Kathy talk about her love and her need to be loved back.

A. (...) Larry had the kind of physical closeness. I guess a lot of it was because I was feeling very ... Like he meant all that much more to me because my marriage had broken up. I really like needed the physical closeness and I really needed to give him all kinds of love and get all kinds of love back. I can remember sleeping with the bassinet beside my bed and with my hand just in it with his fingers around my fingers. Because I just needed that feeling, you know. So it's really, really a mystery. Well, I think it's clearly just brain damage with him.
The discourse of "Encountering Autism"

Up until 18 months, Larry was a happy child who responded to his environment in a variety of ways. In pictures taken around his first birthday, he was smiling a lot looking right into the camera. He was very attached to his mother at that point.

A. (...) I can remember when he was like old enough to stand but still very young. I would have to go to the underground garage for the car in the morning and he cried. He didn't want to stay upstairs with his brother, and I couldn't carry him because it was winter and it is an outdoor stairway and slippery and everything and I had to go get the car and bring it out and he didn't want to be left for even five minutes. So he did have you know, attachments and then he lost it all. He changed.

Q. When did he change?

A. After 18 months.

It is quite shocking to see a totally different Larry on the pictures that were taken on his second birthday. His face does not show any emotion and he is looking away. He seems really distant, a child who does not care about his birthday, his cake or his presents. From then on he did not acknowledge or care about anybody for many years. His non-responsiveness was very alarming and upsetting for Kathy. She felt a real sense of lost.

A. But you know, we just thought; he's gone. You know, he's just gone. This is what he is gonna be, he is just gone. He is not, he is not, he didn't have a
personality, that you could get to know him. You'd just
took care of him, you'd never get to know him.

Larry's detachedness was especially hard to take on special
occasions. Kathy felt like a failure because she could not make
Christmas or his birthday a happy occasion for Larry. Eventually
she made the decision to celebrate every occasion despite her
son's obvious disregard to those special days.

A. (...) What happened on special occasions, even
like Christmas or whatever, that he doesn't care. He
would have presents, he doesn't want to open them. When
he opens them, he doesn't want them anyways.

Q. He didn't show any interest?

Q. He doesn't give a hoot. But because of my family,
we have, we think a lot about tradition. And if we have
a birthday party, we sing happy birthday. He got the
cake, he got the presents, pictures, just like
everybody else. And my mother and I agreed. We just
said; 'I don't care if he doesn't get it. It's for us
then. We will do it for us.' You know, because we're
not gonna let his birthday go by. Maybe he doesn't give
a hoot, or he thinks we're crazy. But it's his
birthday, and we're gonna have a party, and that's it.
I still have to blow the candles out for him, he cannot
do that. He'd go (she's imitating Larry's effort to
puff). (laugh) And he's still, there is no present that
he really cares about. He will open them now. But than
he looks like; so. (laugh) He doesn't care.

Even major changes did not seem to effect Larry's non-
responsiveness. He was placed into a group home at age eight on a
temporary basis and five months later moved to the group home
permanently. He did not show any signs of disapproval of his new
living arrangement. He did not seem to care when he was dropped
off or when he was picked up. No sign of emotion could be detected on his face.

Besides his non-responsiveness, Larry displayed a variety of behavioural problems. Around year five, these behavioural problems climaxed. Kathy reached a stage when she could hear Larry making noise even in her sleep.

A. (…) Sometimes he would make that chimpanzee noise for 18 hours. If he was awake he was making the noise (ah, ha, ah, ha ah) non-stop and so my ears would be just ringing, like I can't stand it! But that's when you know when he was really bad and I don't know what that noise was all about but if he was awake he was making that noise.

Larry spent hours and hours throwing his blocks in the air. When he got at his worst, he would throw everything at the wall. In order to prevent any injury, Kathy had to take all his furniture out of his bedroom and leave him with a mattress and a rug. At that point Kathy had to learn to control Larry's physical outbursts.

A. (…) He was very aggressive and angry and frustrated and noisy and it was lucky that he wasn't too big because I'd throw him over my hip and his legs flying and if he had a tantrum I'd just pick him up and carry him away.

Kathy had to cope with other behavioural problems as well. Larry was in panic whenever he had to go through a corridor. He would put his arms in front of his face protectively and scream when he
had to go through them. Water fountains terrified him too. Later on Larry was issued an antipsychotic drug. This medication helped to calm his irrational fears. Now Larry is fascinated by those things that used to scare him. Kathy assumes that Larry might have a visual perception problem and that is why he was terrified of certain things. However she cannot explain why those phobias turned into fascinations. She just adjusts the way she conducts herself with Larry. She no longer has to avoid corridors or water fountains any more.

Unfortunately some of Larry's behaviours are still unpredictable. That is very frustrating for Kathy but she is able to look at the situation as objectively as possible. She is totally aware of Larry's limitations and her expectations of him are realistic. Of course that does not mean that she is never disappointed with situations.

A. (...) I brought him home on Mother's Day, on Sunday, because, you know, I wanted to be with my son on Mother's Day, and we have had some really nice, enjoyable times together. And I thought, this is gonna do me a lot of good to spend a nice day with Larry. And he was not here. He was not here. He didn't care, he was distracted. Who knows if it was a head ache but it was really ... You know, that upsets me. When you're looking forward to spend the time with him and he just is having a bad time. And yeah, I miss that. I miss having, you know, that I can never really plan to do anything and count on it. At Easter, he was very upset. And I tried to take him to a show, to a matinee and we had to leave (chuckle). He was making so much noise, you know. But I was disappointed. I wanted to take him, I wanted him to enjoy it, I wanted us to do it together and we couldn't. I don't blame him. I don't get angry with him and think, you know: 'Why cannot you behave?'
or whatever. Because he cannot help it. You can just see that he cannot control it, you know. It's just disappointing, that's all.

Although Kathy knows her son really well there have been occasions when even she is shocked by Larry's reaction. Several years ago Kathy decided to spend a short vacation with Larry. This was their first vacation together in a long time. They spent a few days together in a trailer park. They had a wonderful time together swimming and walking on nature trails. After driving her son back to the group home, Kathy was heading up north again to the trailer park to spend an other week there. Kathy's voice is still trembling when she describes what happened afterward.

A. (...) That was the one time that he did have a tantrum when I took him home (group home). And it was after I left. And he had such a bad tantrum, that they called the police. And he put a hole in the wall in his bedroom. And the group home called Peter who was still living here. And they said: "You have to come down, we've called the police, we cannot get in touch with your mother. We don't know what to do with him." And Peter went up to the group home and he was just having a terrible tantrum, pulling hair, biting, and kicking, and throwing, and stumping, and whatever. And the police were there and they didn't know what to do with him but that's the procedure.

Q. That's the procedure?

A. He assaulted a couple of the girls. One of them had to go to the hospital. He ripped out a chunk of hair. And the other one, he grabbed her breast and actually like put a big purple bruise on there. And he wasn't happy to be brought home, (chuckle) to say the least.
What was the reason behind Larry's unprecedented outburst? Kathy is still not sure. Was he upset because he wanted to spend more time with his mother or at the trailer park or both? It is also possible that a totally unrelated event triggered Larry's tantrum. There have been other incidents that makes Kathy wonder what she really means to her son.

A. Sometimes upsetting things happen and you don't know whether to be happy or sad. Two years ago on Mother's Day, my mother asked me to have my picture done, professionally. Because all she'd had were really bad snapshots. So I did that for her for Mother's Day and I gave one of the picture to the group home in a plastic frame for Larry to have. And Karen (group home supervisor) phoned me, and she says: "Is it okay if I take the picture away from Larry" And I said: "Why, what's wrong?" She says: "Because he got a clutch on it, he holds it to his chest and he cannot stop crying." (chuckle). Oh, I thought, and I'm at work, and I was crying. And I could picture this poor little kid hugging my picture and crying. It's good, because he knew it's me and he's hugging the picture crying, but it's bad. I didn't want him to be unhappy. So we took the picture away (chuckle). He has different kind of pictures of me now doing all kinds of happy things.

For several years Kathy did not receive any feedback from her son. He would not acknowledge her or Kathy's mother who had taken care of Larry for many years. He did not show any sign of recognition when she picked him up after work. He would not greet his mother or his grandmother in any way. This was devastating for Kathy who was desperate to receive some kind of "human" response from Larry.

A. (...) But I think for me the worst part was that
he got to the stage where he didn't care if I came or if I went and when I would go to work in the morning and my mom would be holding him and saying 'Wave good-bye to your Mommy' and he wouldn't wave, he wouldn't look, he'd just be looking around. And when I would come home and say, "Hi Larry, Mommy's home! Mommy's home, Mommy's home" he would look up and he would look away, he wouldn't care.

Kathy had to be very patient. Larry was ten years old when he first began to show signs that were clearly his signals of recognition and his attachment. There is still excitement in Kathy's voice when she talks about that experience.

A. (...) They would say to me: "When we told him you were coming he got excited and he's looking forward to it." And he began to do that the girls would tell him I was coming and he'd get excited and he waited at the front door. This is something really new that he didn't do before. And then he started to express affection, you know, with hugs and kisses and rubbing my cheek (This is Larry's sign for 'Glad to see you'). And jumping up and down and giggling when I got there. I would come in the front door and he'd immediately grab my hand and try to take me out. He's ready to go. And I'd say: "No. no. We have to get some clothes, we've got to pack your bag." So I was beginning to get, like he was glad to be with me. I knew that for sure.

Kathy feels that now she is getting the kind of emotional reactions from Larry that she needs. Larry's simple signs of happiness to be with his mother satisfy her. She has fought for her son's feelings and she enjoys every form in what it manifests itself.

Like every other parent who has a child with handicap, Kathy had to go through the grieving process (Witcher, 1989). For a
while hope and denial set in and Kathy went to bed every night hoping that she would wake up to see a 'normal' Larry the next morning.

A. For one thing, he was always such a beautiful little child. And he would fall asleep at night. And I would go in to kiss him on the forehead and make sure that he was OK. And he just looked perfect. Like you couldn't believe that anything was wrong with him. It was like, I was so sure I could just kiss his forehead and he'd wake up in the morning and he'd be fine. Because you could ... He just looked perfect. And even my father ... My parents were very troubled about all of this. And my mother phoned me one day and she said: "Your father is making me crazy. He's made me phone. I want you to know this is not my idea, he made me phone. He wouldn't phone himself, but he's renting and raving in the house, because he had a dream last night; that Larry spoke. And his dream was so vivid, that he's absolutely sure that Larry is speaking today. That he spoke." And I said: "Well, no. Tell him there's no talk (chuckle)." No, you know, my father's having dreams that Larry wakes up and he speaks. That's the way it's affected us.

By her report, Kathy was never angry at Larry for not being a 'normal' child. She did not blame anybody for her son's condition but she did envy people who seemed to have it all; a family and normal children. Kathy was not only grieving over her son, she was also mourning the break up of her marriage.

A. (...) Like when I used to go with the kids to the mall and I'd see a husband and a wife and the little kid in the walker, they're all shopping together. I would come home and cry. 'I should have my husband with me, I should have a normal child with me, I shouldn't have these problems. And how come I'm alone.' I'd cry for hours and then I'd get over it. No matter where I
went, I'd see a family or a situation where I'd say that's what I want and I cannot have it. It was that time in my life that I was sorrowing over what I had lost. I didn't want to be pushing the baby carriage by myself.

Kathy went through a period of time when she did not want to talk to anybody. She felt depressed and very hopeless.

A. (...) For a long time I just really felt frustrated and real sense of loss. That you know, my baby's going somewhere, leaving me that he was retreating. And you know I couldn't stop it. Nothing you could do. (...) And that really, you know, you just felt there's nothing we can do, there's nothing. He's just gone and there's nothing we can do.

Eventually she did accept that Larry had autism and that his condition was permanent.

A. (...) He looked like as if he's a puzzle. If I could just find the missing piece, if I could just reach him, then everything would be fine. It was just, once you break through then everything is fine. And as time went by, we did break through, and he formed relationship with me, with his brother, with his grandparents. He had some favorite teachers and little friends, and things that he enjoys doing. And you know, as I was telling it to you; we were watching his personality develop, because it was like he was not a person before. But even after we reached him, it wasn't all better. There was still the piece missing.

Along the process of grieving, accepting and trying to plan for the future, Kathy has progressed and regressed many times. Now that she is satisfied that Larry's life is on the right track she has started to contemplate how her son's autism has affected
her life.

Q. Do you ever go back to grieving?

A. I'm embarrassed to say, I don't go back to grieving any more. I do kind of wallow (chuckle) in self pity at times. And I get to 'poor me' and I get down sometimes and it's all about me. I'm not really feeling sorrow about for Larry but more specifically about what it does to me. I get over it but. My disappointments and grieving, a lot of those things are gone.

Q. Why is that that you don't feel sorry for Larry? You said that you feel sorry for yourself sometimes but you don't feel sorry for Larry.

A. Not as much as I used. I think mostly it's because at the group home and at school and at my parents' house everyone wants to do what's best for Larry. They want to make his life happy and pleasant. He has a lot of people who really care about him and want to do whatever it is that he needs. When it gets right down to that I do whatever he needs. Sometimes I resent doing it but I do it anyways. He always has his needs met. And I don't worry about him. When he first went into the group home or he first went to different schools I worried. You know, is he gonna run, is he gonna get off the bus, does the teacher know she cannot turn her back for a second, and what if he learns how to open the front door. I worried about everything, his safety. But years have gone by and people know how to care for him. I don't have those worries or concerns anymore. I don't feel sorry for him anymore. I think he's his own person, except for his really unhappy days he has a good life. (....) He is having a good life. He's having a happy life. His biggest frustration is when he needs or want something and he cannot speak. Then that's when we really relate and I have to tell him that I understand him. But I don't have the continual feeling sorry for him, that he's missing out on something. I think he is fine. I think he's fine. I think he'll be happy. To a great extent he doesn't know
what he's missing. Some things he does, like his frustration with not being able to communicate his needs. He knows what he wants, he knows he cannot communicate it and it makes him angry. But most of the things he's missing out on, he doesn't understand what it is. He doesn't miss it. I don't feel continually sorry for him.

Throughout her struggle with Larry's autism, some times Kathy has felt really related to him, especially during those times when she was going through her divorce. There were moments when she felt united with her son. They were like two people who did not want to talk to anybody, did not want to be disturbed by anybody. On some level, they merged and they felt peace inside themselves.

A. (...) And I'd take him to the sand box, you know, at the apartment building and he was just playing with the sand by me. And I'd just sit there and read my book quietly. And I thought, you know, two people who just don't want to be bothered right now, you know, we wanted to be left alone. And so we kind of enjoyed being alone together. At least I did. I thought, it's kind of effortless. I don't have to be boisterous and play tag and catch and everything. I can just, you know, be with him.

Q. There were no demands on you from him.

A. Not, not then. He didn't want anything. It was comfortable for him for me. We were just at ease, together. And at times like that I'm not grieving that he's not talking to me. I'm thinking; 'This is fine just the way it is. We're doing just fine.' And so for that time I'm quite happy with him enjoy myself with him and not looking for anything else. This is a quiet time.

Occasionally, she still experiences this untidiness with her son.
at his later age.

**The discourse of "Fruitless Sacrifices"**

Perhaps Kathy is still grieving on a different level. This grief is not related to her son's autism but to her inability to affect other parents' lives who have a child with autism. When Larry was four years old, his mother enrolled him in a Saturday Program run by the Support Organization for Autistic People. Larry has been attending this program ever since on a regular basis. Taking him there is a very emotional experience for Kathy. Her son is almost a grown up man and there are all those little four year old children with autism doing the same things that her son used to do. This is the time when she is strongly reminded that autism still exist. She almost feels betrayed and cheated as though her sufferings were in vain since other parents still have to endure the same experiences that she has been through.

Q. You mentioned that you don't like to go to the Saturday Program because you see all those little four year old kids with autism. I really felt you had lots of emotion when you talked about it.

A. Yeah, I find it very upsetting to take him to the Saturday Program. I take him because he enjoys it so much. He just loves to go there. But for me, I see men that are at the Saturday Program, that are like Larry, only worst and older and bigger. Men that are 6 foot 2 and 200 pounds, barging around and doing the head slapping and that. It's scary. And there're all these little wee autistic kids. And I just think: 'What's ahead for these kids?' It's very sad. The parents at
that early stage, they don't even know what's ahead, they don't even understand how difficult it's gonna be. And maybe it's better that they don't know because it's better to find out a little bit at the time and not all hit you in the face. I feel very sad for them. And I see mothers that are coming to pick up like a 25 year old man from his Saturday Program and I think all the years she's put in and obviously not a lot of progress and I feel sad for her. And it makes me feel like it happened before Larry, it's happening after Larry isn't it going to end at all? That's the feeling it gives me, it's not going to end. We're not the end of it. It continuing. More and more people are coming with the same things that I went through. So I don't even have the hope that well this won't happen to anybody else ever.

Since his early years, Larry's ability to cope with various situations has been limited. This has an effect on Kathy's life who often feels frustrated by this limitation. She does not blame Larry, but she cannot deny the fact that she has missed out on many things that could have make her life better.

Q. And things that are related to you and Larry, do you have any doubts or regret there?

A. The way I handled it?

Q. Yeah, handled it personally.

A. I didn't have a lot of resentments when he was younger. You know, I was still so busy with mothering, the little baby, the little child. And in a way, you know, you want to do that anyways. So in many ways it is satisfying whether there're any problems or not. Now, I, right now, I find I do have more resentments now and I'm really in touch with them when I'm upset. I've had to accept some realities of the situation, you know, I'm just not very happy about it but that's the way it is.
Q. Such as?

A. I always thought, when like when I separated from my husband and Larry was just a baby, I always thought: "Well, I'm only 32, I'll get remarried sometimes, you know. Right now, I have children to raise, later it will be time for me." And then I thought, "No, got to get Larry established at the group home, settle him down and then it will be time for me. And then it's always been like not time for me yet (chuckle). Yeah, so there's been a lot of different stages in his development. And in a way that affects me. But as far as the way I feel now ... I used to feel that eventually, I'd have almost a normal life (chuckle). I really don't think that's possible. I don't think it will happen. Because I'm not willing to do ... I'm not blaming other people. I just take the responsibility myself.

Q. Uh hum. Uh hum.

A. I'm not willing to do what I would have to do in order to do that, you know. I mean, people cannot cope with Larry. And he's my son and he's always gonna be part of my life. He's gonna be coming home. And I don't know what he's gonna be like when he's older. If it's tough for me sometimes to deal with him, I don't know what's it like for people that just walk in and meet him. You know, new and don't have any history with him. Don't have a relationship. They don't, you know, love him or anything. I mean, if it's hard enough for me, his mother, it's got to be really hard for others.

Kathy has given up hope that she will ever meet somebody who would love her enough to accept her son. Not having a stable relationship is a big sacrifice for Kathy. Along the way she also has to make little sacrifices all the time.

A. I haven't been to an Easter service in 10 years. He's home, I cannot take him. That's it, cannot go. But at Christmas time, they had the candle light Carol
service at the church, and that was on the 23d. And he was supposed to be home. And I just said, "It's important to me, like it's Christmas, I wanna go to the Carol service." So they kept him for an extra day, and I picked him up the next morning. And I got to the Christmas service (chuckle). Because I know, you know, I'd be just so resentful if I cannot do any of those things.

In spite of all these limitations, Kathy does not feel that she has sacrificed too much for Larry. She is able to look at her life realistically and weigh it by balancing the things that she has learned from this experiences with the things that she has missed out on.

Q. You don't feel that you'd given up to much for Larry?

A. No. No I don't. I really don't. I mean, I'd given up something yes. And I think Peter's life would have been a lot different. But there again, you know, I don't think he's been hurt by it. His life has been different And there were some things he couldn't do. But he's also learned a lot and gained a lot. And it's just been different for him.

Q. Do you think it's the same for you, for your life? If Larry was different your life would have been different but maybe not better.?

A. Yeah, yeah. For example; I don't think my marriage would have split up so soon. Not that Larry caused it. But when you're already in a troubled situation and then this new baby arrives and the baby is sick. And you've got to quit work and then the money problem starts and so on and so forth. There was too much strain on an already bad situation. That's all. We'd probably hang in there for a few more years but whether that's good or bad, who knows. At the time, I felt it
was easier with my parents to raise the kids than to be alone in a middle size community with no help from my husband. And I probably, you know, I probably would have remarried if Larry had not had any problems. But I've been really disappointed with some of the attitudes the men had I've gone out with over the past 18 years.

The discourse of "Everyday Living, Stress and Coping"

Kathy experienced a lot of frustration during Larry's childhood. Just trying to get him ready, and send him to school each day was an enormous chore. This struggle every morning did not leave much time for Kathy to prepare herself for work. Larry was resistant to almost everything that was offered to him. At one point, he began to eliminate foods until he was eating only puddings, one type of canned soup and canned fruit. Kathy knew it was not good for Larry. With the help of her support worker from Parents Helping Parents, she designed a program to teach her son to accept a variety of foods. Following the program was extremely stressful for Kathy. Larry was offered food only at meal time. If he did not eat it within a certain amount of time, it was taken away and nothing was offered until the next meal. This process was followed very rigorously. Larry would not eat anything for three days but then gradually he began to eat everything. Although this program had worked, Larry's resistance did not let up in other areas. Kathy did not take his resistance personally, she never felt that Larry was rejecting her. Larry was rejecting everything and Kathy happened to be part of that. However, all these everyday struggles left her feeling very
frustrated. She thought that as Larry's mother she should know how to reach him and since she could not do that she was failing.

Kathy used a variety of self-help activities such as going for a walk, jogging, listening to music to get through the day. These self-help activities were like a First-aid Kit for her, being available at any time unlike other type of help that were on a schedule or appointment. Kathy is very insightful when she talks about how running helped her deal with her stress.

A. What I used to do, I don't do that anymore (chuckle), I should. I used to jog, I used to run. Actually, I used to do like 5 k (km) a day and 10 k on the weekends. And it's physically exhausting, mentally it's very good. What else you gonna do when you're running. Your mind kind of, I don't know. It's difficult to explain. You could have a problem and you don't know what to do about it. You go out and jog for 5 km, by the time you get back it just doesn't seem such a big problem. And you have some ideas what you might do. Your mind is totally devoted to thinking. No distractions, no phone, nobody can interrupt you. You're unreachable so have time to sort it out in your mind. And it really... You know, they talk about runner's high, when the people who exercise mental therapy. And it's quite true. It helped me out a lot.

Kathy was experiencing some financial hardship as well. Larry's annual summer camp, especially designed for children with autism, cost more than her salary for the summer. Money was tight during the rest of the year too. Sometimes Kathy had to ask her parents to help out.

Kathy often wonders whether she would have survived the first ten years of Larry's life without her parents support. Her
mother, Barbara was really sensitive to Kathy's personal needs, often offering to keep Larry overnight so she could get a good night sleep. Also, once a week, Barbara babysat Larry while Kathy took Peter out for dinner to spend some quality time together. Barbara went along with Kathy to Larry's medical appointments as well. Beside the hands-on help, Barbara and her husband were always there for Kathy emotionally. She was able to share her worries with them and they have proved to be good advisors. The three of them have always made their decisions together regarding Larry's care. Kathy feels very fortunate to have that kind of support.

A. (...) When you want to make a decision there's nobody there to say to you: 'That's right, that's what you ought to do'" Nobody to confirm what you've planned or nobody to say: 'Did you think about that twice?' You're just on your own, you know. So I got in the habit of really discussing things like that with them. The kids, I'd more discussed with my mom. And everything else, like business, finances and buying cars and everything, I went to my dad. Because I wasn't really comfortable making decisions by myself. Even if I'd decided what car I wanted, my dad went with me when I bought it and we'd test drive it. And he'd say: "Yeah, this is good for you, all right." Then I was more comfortable with my decision. If they hadn't been there, I don't know how I would've managed. Really, you need that, somebody to reinforce what ... Not to make a decision for you, but bounce ideas from.

Q. Yeah, and I think even just sharing your thought and having somebody to listen and have an interest.

Also, Kathy has a best friend. Their personalities are very different. Things that represent a huge problem for one of them
is easily solvable to the other one. Kathy assumes that is why they can help each other. Kathy and her friend have an agreement that they can call each other at any time, no matter what time it is. Both of them have resorted to calling the other one on some sleepless nights. Her friend, like her parents, has been through the process of Larry's diagnosis and subsequent developments. It is very comforting for Kathy that she does not need to explain anything to her friend. The other type of informal support comes from Kathy's colleagues at work. She has been working at the same office for several years. Kathy, who sometimes arrived at work feeling really depressed, has learned to appreciate even the smallest sign of caring.

Q. How did you deal with your pain when you were discouraged when you were upset that he wasn't the way you wanted him to be? How did you deal with it?

A. How did I get passed through it? I don't know if I really did. You just do what you have to do. What else are you gonna do? I mean you either do it or you're gonna quit and I wasn't ready to quit. Wasn't ready to give up. I guess a lot of ... Just when I'd really, really be discouraged and think like, you know, how bad can things possible be, and then something nice would happen. Some little nice thing. And it doesn't take a big thing just some little thing. And I'd think, you know, maybe everything will be OK now. I mean one nice thing happened, maybe more nice things will happen. And I know that's really changed my attitude about the way I act to other people. (...) I still think a good part of it was that I was at the same job for a long time. And the girls I worked with were good friends and I could talk with them. They made sure that things were celebrated. I always ... I never had a birthday that I didn't have the girls at my office would take me out for lunch, you know. And we would have a cake in the
afternoon. I mean, they do it for everyone (chuckle) not just for me, but nothing would go by unnoticed. There'd be always some little celebration. And those things do make a difference. That, yeah, someone doing some little thing to lift my day. And they probably have no idea (chuckle) but it made a difference to me. But, I mean, it doesn't mean it doesn't hurt anymore just helps. It gives you some hope that maybe things are gonna be better.

Kathy's main form of formal support came from a worker provided by Parents Helping Parents. This support worker, who Kathy refers to as the therapist, also has raised a son with autism. Kathy could respect her opinion since she had learned how to care for a child with autism from experience and not from books. This support worker went to Kathy's home every Tuesday night for many years. Each occasion, she spent two hours teaching Kathy how to work with her son, teaching basic self-help and social skills.

When Larry was nine years old, Kathy moved to a little town north of the city and settled into an apartment in a cooperative. She did not want to be a stranger in the crowd anymore. She feels more comfortable in this little town where everybody knows everybody. The small town seems to work well for Larry too. People there have accepted him very well.

A. My neighbours know him. The one time I had a complaint about the noise, it wasn't even directed at me. My neighbour said: "I don't know who's doing all that hammering but it's driving me crazy." We were just talking outside. And I said: "Oh, I'm sorry. That's Larry, he's upstairs and he's pounding his blocks on the floor. And if I put a rug in there he'd find
another place to find a hard piece of floor. He likes
the noise. I see what I can do and get him interested
in something else." And she immediately said: "Oh, I'm
sorry. It doesn't matter, don't worry about it." She
was sorry that she even mentioned it. So they're very
accepting in this cooperative. That's another reason
why I like to stay here.

Q. And it's good for Larry too.

Kathy has learned to believe that people with handicaps have
just as many rights as anybody else. Also, in this process, she
has learned to be an advocate for her son. She believes that
since he is unable to speak for himself as his mother it is her
job to express his needs and fight for his rights.

A. (...) If I go anywhere and I have Larry with me,
like if we went to a Swiss Chalet on the weekend, and
I tell them when I arrive "I can't wait in the line,
if you can't give me a table I can't stay, my son
can't wait for half an hour." They get me a table.
You don't get what you don't ask for. People, are
helpful but they're not going to do what you don't ask
for. I wrote a letter to Canada's Wonderland last
month and just that you know, I think that my son
would enjoy Canada's Wonderland but it is very
expensive and he's autistic and I can get there, and
he might decide in half an hour he doesn't like it, he
wants to go home and I'll have to try three or four
times before he will accept the place. Then he will
enjoy it. They sent me two free passes! So I can
introduce him to it and he knows the place, then I can
buy my family pass when I know that it's okay. Yeah,
you get really nervy when you have a handicapped
child. You get mouthy.

Once Kathy 'ran' away for a week to Florida. Barbara was
taking care of the boys. Kathy had a week just to herself. It was
off season. The place was deserted. She walked on the beach for
hours and did not talk to anybody. She needed the peace and quiet. Without a partner who could protect and guide her she has learned to draw limits to things that she could not do without regretting later on. That was one of her ways of self-preservation. She felt helpless to contribute in a meaningful way to different parents organizations as she did not have the resources to cope with the added responsibility.

A. (...) They wanted me to join the parents group at the Treatment Centre. And I went to a couple of meetings and it was very upsetting for me. I told them I wouldn't be coming. To spend a whole evening talking about the problems and difficulties and what are we gonna do and we need funding and are programs are being cut. And I would come home a wreck. I cannot deal with that. I can deal with the realities of me and Larry and what I'm teaching him and how we're getting along and one-to-one. But to deal with that magnitude of problems, I cannot cope with it. You know, in the past maybe I would go and just be upset. And I would just think it's some thing I have to do. No, I don't feel that now. I cannot do that, somebody else will have to do it because I cannot. It stays with me too long for days after. And that's not good. I cannot be doing that. I cannot be upset for three days because I went to a meeting. So I don't go. Bad attitude (laugh).

Perhaps placing Larry in a group home was an act of self-preservation as well for Kathy. Now she and Larry have their routine. Every second weekend Larry comes home and Kathy devotes her entire time to him. She often visits him during the week at his group home as well. Although she has done much for Larry, she still questions her abilities as a mother. She compares herself to those families which all unite in order to raise a child with
a handicap. In comparison she feels she has not done enough and thus does not consider herself a good mother.

A. I'm surprised, like one of the girls at work just mentioned in passing: "Oh, you're such a good mother." "No, I'm not. What made you think of that. I'm not such a good mother. Are you kidding?" Because I see what people go through with their kids. And some families are just so totally devoted to their autistic child and they do so much. And I think: 'No I don't do that much' I have my own weekends. I'm good to Larry and I'm concerned for him, you know, but I take care of myself too. I'm not totally self-less in the whole thing. (chuckle) It's just surprised me that she would think that my whole life is Larry, and that I'm totally dominated by that situation. And it's just not like that.

Q. But do you think being a good mother means that you're totally devoted?

A. Maybe? Maybe? I mean they're doing more than I'm doing. If doing more is good they're better. I don't know. I guess that's a very complex question.

The discourse of "Getting Adequate Treatment"

The circumstances around Larry's group home placement were partly accidental. Kathy took sick at work and she was taken to a hospital by ambulance. She had to have a surgery on an emergency basis. Barbara, who was trying to care for the boys while Kathy was at the hospital, could not cope with the situation. She called the group home where Larry had been going for parent relief to see if they had an emergency program. The program was available and Larry moved to the group home. At that point,
everybody assumed that his stay there was limited and he would come home once Kathy recovered from her surgery.

A. (...) When I was getting better and then I phoned them up and said, "Well, I'm going back to work, I'm fine, I am going to come and pick him up" and they said, "Well, think about this that now it's June, and pretty soon school is over and you have the problem of finding programs for him for the summer, why don't you leave him here for the summer, except for the time that he is in summer camp and I will solve your problem, he is quite happy here." So he went in there on a temporary basis, then when September came (chuckle) you know, I got together with him, and said: "What do we do now?" "If it is working out for you, and it's working out for us and he's got his room mate and the boys all get along, you might not get a place if you wait." So I talked to my mom about it and everything. We had visited a lot of different group homes before knowing that this would happen and.... my mom liked the people at this group home and she liked the facility being very safe, even though it's a bit institutional, you know, but it was safe and Larry at that time couldn't live in an ordinary house. It had to be a coffee table that wouldn't tip over if he stood on it, and all kinds of things like that. So we knew he was perfectly safe there and I wouldn't have to worry. So, well like physically, safe.

Kathy had had many frustrating experiences with the system before she placed Larry in the group home. After Larry was diagnosed, she was receiving financial assistance for an after-school worker. The funding for that had to be renewed every six month. It was a very trying process. Every six month they had to set new goals for Larry. It was a great challenge to set the goals in a way so that they were almost but not quite achievable. Despite all these struggles, the government funding for this worker was
cut back several times, eventually leaving Kathy with no after-school care for Larry. She had approached the group home that provided parent relief about providing a before and after-school program for Larry. They could not accommodate her as they did not have funding for that kind of a program. At the time, emphasis was not placed on helping families to keep their children at home. That did not leave Kathy with many options. She did not want to stay at home on social assistance. Her intention was to keep her job and to care and provide for her other son as well.

A. I was just not happy for the whole thing, like I wanted him to be with me but half of me would say, you know, you have another son, you're also an individual and you've got to have some life for both of the two of us, and Larry had changed our lives a lot. We had to make some kind of arrangements so we wouldn't just be spending the rest of our lives taking care of Larry. And that's you know, it's not a nice decision to have to make to kind of save yourself at that price.

Kathy, with her parents did make the decision to place Larry at the group home but it took Kathy a long time to learn to live with her decision. At first while driving him back to the group home and on the way to her home she cried in the car. Although she knew that Larry was fine, she was not. Larry who was nine years old at that time seemed happy with his new living arrangements. It was upsetting for Kathy not to see a negative reaction or disapproval from Larry of his new living situation.
Q. So, then why were you upset about taking him, when you said you cried when you would drive him back. If you thought that he was okay at a safe place and he didn't show any sign of rejection?

A. No, I knew that he was okay, but I you know... part of me would have happier if he had been crying: "Mommy, don't leave me". He never did that.

Looking back, Kathy still thinks that with the right before and after-school program she could have kept Larry home for another three or four years. She feels that his placement was premature. Although she does not think that keeping Larry home for those extra years would have made a difference to his development, it would have been better for her since she would have had more adjustment time.

A. (...) It's very difficult to put your child to a group home and if parents can avoid that if they get the support they need then they don't have that upset, they don't have to deal with that separation or that decision, anything.

Placing Larry in a group home was not a gesture of giving up. It was creating arrangements that could work for everybody.

Kathy has had many frustrating experiences while trying to attain adequate medical treatment for her son. Larry was put on medication at a very young age to control his seizures. Larry was not epileptic, his seizures were caused by a trauma at birth. At age four, Larry's behaviour started to get out of hand. Kathy became convinced that her son needed medication to calm him down. An episode during which Larry was jumping off the bed and throwing toys on the wall for 48 hours without any sleep,
prompted Kathy to go to a specialist. She wanted to find a solution to this unbearable situation. In order to persuade the doctor that Larry needed some medication, Kathy had to put up a desperate fight.

A. (...) And Dr. Smith said, you know, that he didn't want to give him any medication. And I said: "Look. If you're not gonna give him something, then I'm gonna leave him in your reception area. Because I haven't slept in two days. I'm just gonna leave him here and go home." And he said: "You mean he's been doing this for two days?". I said: "He hasn't stopped in 48 hours and I have to sleep. This is crazy. Besides, it's hard on him. He hasn't even stopped eating. He's just burning calories.". Obviously, he needed something. You know, I mean that's not right. Most normal people couldn't carry on with that level of activity for more than an hour, tops. I don't know where he got that energy from. So then the doctor said, he'd try Mellaril. And it worked right away. He gave him minimum dose, it was enough to help him calm a bit.

Kathy has also struggled continually to obtain appropriate dental treatment for Larry. Based on her experiences, she is convinced that the only way a dentist could clean her son's teeth if he is administered anaesthesia. He is just too terrified to open his mouth willingly. Kathy has found the dentists she has encountered so far very condescending. They will not consider her opinion.

A. No one believes you. They don't believe me, they don't believe the girls at the group home. Finally we found a dentist. I said: "You're gonna have to give him an anaesthetic, you will not be able to do it without it." They won't believe you. You hear: "Oh, you'd be surprised. We worked with handicapped children all the time." Then they meet Larry. He's not gonna open his mouth and let you put in instruments and have a look
around. Forget it! The one time he had good dental care was at Highland Hospital. They put him under anaesthetic took him in the operating room and thoroughly cleaned his teeth. He just had two little cavities. Thank god, he's got good teeth. He hasn't had good dental care ever since then. We've found another dentist that specializes in taking care of kids who are in the Metro Associations. Same story: "Oh, you'd be surprised, we deal with these kids all the time, bring him in." Right. The guy gave him tranquilizers before the visit when we arrived there. Then he had gas, then he was in restraints. Then he froze the spot and then there was Karen (group home supervisor) and I and the nurse holding him down. And he fought the tranquilizers, he fought the gas, you know. I mean and he's just totally traumatized by this whole thing. I said to that guy: "Are you ready, do you believe me now?" He said: "Maybe we should try a little more tranquilizer?" And I said: "Forget it! I need a guarantee from you that he's gonna be under anaesthetic."

Kathy, who is a fighter, has not given up her quest to ensure that these frustrating incidences will not happen again. She has written a letter to the hospital's chief dentist (where the last incident happened) and sent copies to the hospital's Public Relation Department. In her letter, she has outlined the problems she had encountered, and requested assurance that in the future Larry would be given anesthesia every time when he visits to have his teeth cleaned.

Kathy has had mostly good experiences with Larry's schools. The first time she saw him having fun was at the summer program of his preschool. Larry was five years old then. There they taught him how to bounce a basketball which he still loves doing that. They also tried to teach him how to ride a bicycle but he
never quite learned that. Kathy is especially happy with the Treatment Centre where Larry currently attends. He has been attending this special school for seven years now. She talks highly about this school where teachers are willing to change the program to suit the student instead of trying to plug him/her into an established program. Kathy knows that people who work with Larry need to be extremely sensitive and flexible in order to establish and maintain a positive relationship with him.

The discourse of "Mother as Teacher"

It was an enormous task to teach Larry basic self-help and social skills. There he was, a two year old child who would not establish any eye contact and would not show any interest in his environment. Obviously social rewards did not motivate him to learn new skills. There were only two things that could be used as reinforcers in those early years- Fruitloops and cookies. Most of the programs that were designed to teach Larry some basic skills were developed by the support worker who went to Kathy's home once a week. It was obvious that Larry's self-stimulating behaviour needed to be broken and he needed to be brought out of his own internal world. Larry did not like it when somebody interrupted his perseveration. Whenever this was attempted he would move away with his blocks. When he got really mad he would bite the intruder's hand. Also, Kathy wanted him to show some affection toward her but it seemed so unnatural to feed him with Fruitloops every time he looked into her eyes for a second. She
was wearing an apron with big pockets always filled with Fruitloops. That was the only thing that seemed to motivate Larry. As long as he would sit on the toilet she kept giving him Fruitloops. As soon as he got off there were no more Fruitloops. Kathy who had never believed in programming children had to change her attitude and program everything for Larry. She often had to impose her goals and will on him. However she has always made sure that the goals she sets for him are reachable and would be beneficial for her son too.

A. (…) The other thing he was afraid of is the grocery store. And we figured it out what it was. Because the lady who came for therapy went with me to the grocery store where I shopped. He was terrified there. I had to go shopping by myself because he's afraid. But there were a lot of lights, the cash registers were very noisy, the air-conditioning system was very noisy. The acoustic seemed there just very loud. Everything seemed there just loud, loud, loud. And she just said: "He cannot cope with it. The lights, the noise, the people, the activity. This is just a place where he cannot cope. You have to find a quieter grocery store or go without him." So there again, she had a great idea. I would do my grocery shopping by myself. And I would leave 1-2 items that I wouldn't buy. And then later on I would take Larry to the store, and I would just quickly go in, get those two items and pay for them and leave. He still had to go but not for very long. Now he loves to go grocery shopping. He's fine. And he reads the labels. He knows what brand of wax paper I use. He picks it up. He knows where the cookies are. He picks Oreo cookies every time. He knows, he cannot have them (Larry is allergic to chocolate.) but he wants them. He goes over to the corn chips and brings Nacho chips over puts them in the cart. But you know, that was a slow introduction. Every week I took him just for... We might have been in and out in 5 minutes. I agreed with the therapist, that you
Kathy had to teach Larry a variety of basic skills such as using utensils or putting his shirt on. Looking back, Kathy believes that the only way to teach Larry and other children with autism is to repeat things over and over and over until finally it becomes a part of their behaviour. Once it is learned it is there to stay. In order to carry this process out, Kathy had to be extremely persistent.

Teaching anything to Larry was a very slow process. She often became discouraged by his lack of progress and his strenuous resistance to learning. The therapist kept a chart of his progress. This helped Kathy to realize that Larry had acquired some skills, only at a very slow pace. Putting on his shirt was broken down into twelve steps. It took Larry five month to learn six steps out of the twelve. Now Kathy still has to do the first step and then Larry is able to do the rest of them. There are still some self-help skills that Larry has not learned. In the past, Kathy did not resent performing those skills for Larry but since her son reached puberty she does.

A. (...) I do, wipe his rear end when he goes to the toilet and I have to shower him, brush his teeth, and shave him. And it's very kind of, well I don't ... Kind of humiliating for me to have to do all these personal things for someone who's physically a mature man, my son. You know, it's demoralizing for me.
According to Kathy, Larry is beginning to level off in his progression since his development is slowing. It is not very likely that he is going to learn any new skills. However, she would like him to learn to enjoy a variety of leisure activities that he could get real pleasure from and that they could do together. She has taken Larry to the movies a couple of times. He has been fine every time until the popcorn is gone then he wants to leave. This does not discourage Kathy who hopes that with repetition and persistence she will achieve her goal.

Q. Yes, you're still trying. The show is a new thing that you want him to learn to enjoy.

A. Because I see how the things that he really gets into, he just loves it. To see his face light up and he smiles and he's signing he wants more and he's having a wonderful time like at Lakeshore Gardens. That's just his favourite place in the world, he just loves it there. And of course, we started going there when he was even still little to walk. I had him in the stroller. (...) And you see the thing, I really think, that even though that he was very young, and had this mental handicap, that because we did that so often and so consistently. That's why he enjoys it so much now. It's every time he goes there, he's remembering happy times.

Eventually, Larry did learn how to eat with utensils, he is toilet trained and he looks into people's eyes. His mother is the first one to cheer for his accomplishments. She gets really excited each time that Larry comes up with something new. Larry now understands verbal language which makes it a lot easier for Kathy to connect with him. Also, Larry now understands that daily
events happen in sequence. Since then he is less frustrated and has less tantrums. Kathy is very proud that Larry is showing signs of gender identity as he seeks out the company of males. He has positively surprised her with one incident that could be considered a sneaky teenager act.

A. When he was home at Easter, the little turf. I don't drink very much. So I poured half of the beer into a wine glass and the other half was in the fridge, and he went, he helps himself. He went and he took the other half of the beer. And he comes out of the kitchen slurping the beer. And I said: "Larry" (short laugh). And I took it away from him. And he's greening, glug, glug, glug you know how fast he drinks. And he got about third of a beer. I'm sure it didn't hurt him. I wouldn't give him one. He kept going back to the fridge and bringing me beer bottles. He wants me to open the beer bottle. And I said: "No, you cannot have it, go and put it back!". So I thought, that was over with. Peter comes in later on in the evening, he takes Peter into the kitchen, to the fridge and asks Peter for the beer bottle (laugh). He thinks he tries somebody else, maybe Peter will give him a beer. I guess he liked it. Peter didn't give him the beer either. But you know, "I didn't have luck with Mom, maybe Peter will give me." And I thought, that's good. That's really good. His mind is really working there.

As a young child, Larry did have a way of communicating his needs and wants.

A. I didn't know what he wanted to drink, so I would get his little cup and I would put milk in it. He'd look, doesn't want milk, throws the milk out, hands me the cup back (laugh) "OK, we'll try apple juice!" So I go over rinse out the cup, put apple juice and give it back to him, look in, apple juice? No. Throws it and there was food everywhere, juice everywhere! Finally I hit on what he wanted, he'd look in, yeah, that's it.
Then he would drink it. And I'd just thought well fine, after dinner's over, I'll clean up, (chuckle) and if he got food he didn't want, he would just take the plate and throw it.

These kind of episodes forced Kathy to try a variety of approaches to teach Larry to express himself. She made up a communication book that contained pictures of objects that were relevant to her son. In this book there were pictures of a glass of juice, Fruitloops, Baskin Robbins, music tapes, Kathy's car and the bath tub. This book was introduced to Larry but he never used it for communication purposes. Still, Kathy felt better being able to show him what was going to happen. Since this approach did not work, Kathy tried putting Larry's drinks and cereals in clear jars so he could see what was in them. This proved to make their meal times less hectic because Larry was able to indicate his choice by pointing at the appropriate jar. Since Larry had started preschool, Kathy has made sure that everybody involved with Larry's teaching and care, including herself, followed the same approach while working with him. She is willing to listen to new ideas and strategies and include those in her repertoire if she thinks those would improve her son's situation.

A. Did you know that Larry is beginning to understand, he is beginning to appreciate when people understand him. When he is at home and he's frustrated or upset and carrying on and if I can sit him down talk to him and tell him that I understand him; "I know you're upset, and Mommy knows" and this kind of thing. And I say it really loud and let him know, he changes, like he's glad that I know. And then he gives me a hug
or starts to cry. He knows that I know. And that's good. I thought that was crazy you know. The lady at the Treatment Centre that started to do psychotherapy with Larry. And I said to her: "How can you do psychological counseling with him? He cannot talk, I don't understand why he has a psychologist?" I didn't want to insult her but I really felt it was kind of a dumb job (laugh) because what is she going to do. Psychology is all about talking. And she told me exactly what she does. And I do exactly what she said to me, I set him down, get his attention and I say: "Larry, I know you wish you could tell me what's wrong, and I know you're upset" and she just tells him that she understands. So I do the same thing now and I think he gets it. I think half of it is that once Larry knows that somebody understands then he is not quite as upset.

The discourse of "Hopes and Fears"

From Larry's birth until the present time, Kathy has changed her ideas about her son's future many times. Sometimes the change was caused by a professional's input, other times by Larry's lack of progress. Looking back at this process, it seems like a roller coaster ride. Kathy's hopes have ranged from Larry living independently with minimal support as an adult to not having any emotional reactions from her son. Any minor incidence could raise or dash her hopes until she had reached a true understanding of Larry's condition. Firstly she had to change her philosophy. When her first son, Peter was born with some medical problems, Kathy felt that as long as he was mentally fine they could work this through. All the implications of his medical conditions could be explained to Peter and he could learn to live with them. Then Larry was born. Kathy had to look for a different philosophy
since Larry was mentally handicapped and unable to have
discussions about his condition. Kathy had to work through the
maze of her son's autism on her own. Her hopes regarding Larry's
life have evolved parallel with her son's condition.

Q. What are your hopes now for Larry?

A. Well, you know, they're continually changing. I
used to think he was ... When he was really little,
they said: "Don't have any hopes because he's not gonna
go anywhere." And of course, he did very well.

Q. Did they say that?

A. They said: "You'll never reach him. It cannot be
done. We don't know if he'll ever learn anything
because you just cannot reach him." So he did a lot
better than the original diagnosis. So then we had lots
of hopes that he'd, you know, that he maybe have some
kind of independence, supported life. And that's not
realistic anymore. (...) So my goal right now is to
make sure that he's happy and that he has things that
he enjoys doing. And that's what the show is all about.
And anything, any other outings, it's to find things
that he enjoys doing. I don't want him to be one of
those; sitting around, bored, watching the test pattern
on TV all day. It's really important that he develops
things that are of interest to him that he likes to do.
A big variety of things. Playing with the basketball,
it's not enough. He's got to have some other activities
he enjoys.

Kathy's latest hope is that her son will be able into integrate
to her church community. She would like him to accompany her to
the church on weekends when he is at home. This is a goal that
could take a long time to achieve but Kathy thinks the effort is
worthwhile.
Unlike her hopes, Kathy's fears and worries regarding Larry have not changed a lot over time. Her main concern has always been his physical safety. He has never shown any signs of understanding danger. Danger is just too abstract for Larry to comprehend. His lack of awareness is specially alarming in traffic. He has no idea that cars can hurt him. Kathy always has to be on high alert when she is with him. In parking lots she has to hook her finger through his belt loop to prevent him from running right into the path of a car. Larry has a lot more physical freedom than he can mentally cope with. He learns how to do things physically before he can cope with them mentally. As a result of this he has put himself into life threatening situation without realizing it. This leaves Kathy in a constant state of worry when Larry is under her supervision.

A. And he got out of the house when the first time, and I didn't know that, he learned how to operate the patio doors. The girls at the group home taught him so he can go in and out. Because he cannot get out of their backyard. So in the summer he can walk in and out as much as he wants. He came home here went right out. And he took his basketball and I was frantic. "Larry, Larry", of course he's not gonna answer me, but I kept screaming Larry. I got down to the end, and he's sitting in the middle of the road, cross legged, bouncing the ball with cars going by. He had no idea. That was 2 years ago. He was a big boy.

Although her son's physical safety is still Kathy's number one concern, his sexual maturity has brought new fears and worries into Kathy's life. Larry has no awareness of what is socially acceptable behaviour when it comes to sexuality. Kathy
always has to make sure that Larry is dressed in jeans when they are out in the community. Kathy has learned from experience that if in track pants he would put his hands in his pants to touch himself. Sexuality provides another example where Larry's physical development has reached a certain stage without having the appropriate mental ability to cope with it. This fact has a great impact on Kathy who feels utterly hopeless in this situation.

Q. I know you're worried about his safety, his physical safety. But do you have any other worries?

A. Worries ... I'm concerned, you know, you don't like to see your child in discomfort. And I know that right now, he's going through this, you know, sexual maturity. And he's so frustrated sometimes. He works himself up into a ... And he goes up to his room and he's like humping on a pillow and he's very uncomfortable. And he'd be like that for hours and he cannot masturbate properly. I certainly don't want to show him. You know, it's not for a mother to do. He gets very, he's in pain, you know, it's uncomfortable. The weekends he's like that I'm very ... I wish there was some solution to that problem. I don't know what that would be. That's a concern. It's been a concern of mine for a couple of years since he's been having those difficulties. Any other 18 year old would know what to do, but he's just in discomfort. So that worries me. That's just an unsolvable problem.

The discourse of "Social Reactions"

It is very painful for Kathy that her family has a real problem accepting Larry as an adult with autism. She and her boys used to spend a lot of times with her brothers and their families
when Larry was little. She understands that it was much easier for her family to relate to a four year old in diapers than to an 18 year old who occasionally dirties his pants. It is getting even more difficult now that Larry is having problems with his sexuality. Although Kathy understands the roots behind her family's partial rejection, it still means less support and love for Larry and her. Kathy thinks that her family and people in general should be mature enough to make adjustments in order to include Larry in their lives. The obvious discrepancy between Larry's age and his behaviour often produces confusion and problems for strangers. Larry is very curious around little kids. He is intrigued by two and three year old. When he sees them on the street or in the park, he runs up to them, screeches to a halt and stands there looking down at them. Although he has never hurt any little child, the parents of those children are not aware of that. Just the sight of Larry and his behaviour are enough to prompt them to gather up their kids and leave the area. Kathy has learned to manage those situations with a potential for trouble very diplomatically. She believes that confrontation does not lead to acceptance and acceptance is what she is advocating for.

A. (... ) When we were at the theatre he was making a lot of noises and I was trying to keep him calm and the lady in front of me that had the little kids, she turned around really nicely and she said, "Would you mind moving because my boys are really looking forward to seeing this movie..." it was the newly remake of Star Wars show and I said "Well, I think we're going to be leaving, I don't think this is a good day for him to
be here, sometimes he enjoys it, sometimes he doesn't and today he just doesn't." and then she said: "Oh, I'm sorry." And I said: "That's OK." But she was nice. I think if I had been nasty back and said forget it, you know that would have been a confrontation.

Q. Very likely.

A. But you know what, you see everything....this was a matinee, there was all kinds of little kids there, little rug rats running all over the place running back and forth to the concession stand and their mothers and sitting in the front row and walking all over the place. He was like them except that he is only 6 feet tall and makes a lot of noise. He was not misbehaving any more than the other boys but they were little wee kids. So by comparison you know, he was okay. It's just that he's now so big that that's not acceptable any more.

Kathy has had both, positive and negative experiences about peoples' reactions to Larry. She used to be very upset when her son would make a fuss in public and people would notice. She felt so embarrassed. At that point she was still hoping that he would eventually gain control over those outbursts. This attitude changed over time as Kathy has accepted the fact that those outburst were going to be part of Larry's behaviour forever. Now, she does not care what people think of Larry or her when he is having a tantrum. Her goal is to introduce new places and activities to Larry. In this process she has to take chances since she never knows how Larry is going to react to an already familiar or to a totally new situation. She always has to be flexible and be ready to leave whenever her son is showing signs of excitability. Sometimes Kathy has to scream and yell in order
to get Larry's attention and behaviour under control. She does not find these incidents embarrassing anymore even if they happen to take place in public.

A. We went up to the mall a little while ago and he got to the front door and just went wild. And it was totally out of the blue. There wasn't anything wrong and he just went ballistic; yelling, slapping his head stumping his feet.

Q. He had to be really upset then.

A. And it was just, I mean I kept back a bit because I thought if he grabs me I'm in trouble he is really agitated. But I finally yelled at him and people were watching. I finally yelled at him: "Larry, you don't have to go! You don't have to go!" and I'm yelling so that he would hear me over his yell and he stopped for a minute. And I said: "You don't have to go shopping, you wanna go home, you wanna go to the car?" And he'd go (Signing please). He signs please. I don't know why he felt he had to through a terrible tantrum to give me that message but just didn't want to go. He didn't feel like going through the mall. Maybe, who knows why. I don't often feel like going in there either. But I didn't care and actually some people are quite nice. A lady came up and asked me if she could help me or there was someone she could call. And I said: "Well, no, but we're gonna walk to the car and it would be helpful if you'd walk with me. Because when I go to get my keys I don't want him to run away. She opened the car door and I helped him in to make sure that he wouldn't run into the parking lot. She was helpful, it was nice. So now, I don't care if we disturb somebody. I don't worry about it.

Kathy finds that people are quite responsive if they have been approached the right way. She is keenly aware of people's tolerance level and tries to maneuver within those limits.
A. (...) Last Christmas, because of the strike at the group home, he was home every weekend from November to late February. And a lot of things were going on that I could've gone to. My friends had an open house and they said: "Well, bring Larry, I mean, don't stay at home. You come and you bring Larry. You know, it's drop-in, when he's had all he can take you leave. Don't worry!" And my friends were very accepting, you know, and actually Larry, I got him all dressed up, he looked so handsome. And he wasn't misbehaving. He was just so excited and he was happy to be there. And he went all from room to room to room to all these groups of people (chuckle), and would walk up to the group and would just look somebody right into the eyes until they acknowledge him. And he'd give them chin rubs and he was grinning and he was very well behaved.

Q. I can just picture that.

A. But I could tell a lot of the guests were really uneasy with this. And he didn't make any weird noises or anything, he was good. But he was just, well he was Larry. People who don't know how to take him, I could see that they were feeling strange. And then I thought; "Well, you know, this isn't my party. It's my girlfriend's party, and we've been, we paid our respects and we should leave. You know, not disrupt the whole party." So we didn't stay very long, but I tried.

Kathy sometimes feels stigmatized. She does not have an 'average' life since she does not have an 'average' son. The way her life runs is very different than other people's life in her age group. It is hard for her to share even the basic facts of her life with a new acquaintance. Many times, their reactions have left her feeling very uncomfortable. This shows that although Kathy has accepted her son's handicap, she has not made peace with the life she has to lead as a result of it.
A. (...And I just, you know, even when I meet new people ... I'm not a secretive person, but it's to begin to tell them what's been going on in my life it's like a soap opera. I'm even embarrassed to even tell a person, you know (chuckle). I just kind of play down a lot, casually mention on the side that my son is home on weekends because he lives in a group home. And I don't make a big deal, because people go: "Oh my god!" You know, and it's like very comical, this is just like horrendous. And I don't want that kind of a reaction, you know.

The discourse of "The Other Child"

Kathy often felt torn between Peter's and Larry's needs. After her divorce, Peter was not seeing his father at all. She wanted to be there for him all the time, to communicate with him and to have a good relationship with him. Many times this was impossible since Larry was such a high need child. Peter missed out on many activities that they could not attend because of Larry's behaviour. Fortunately Barbara was very sensitive to Peter's needs and she did her share to help out. When Peter was eight years old, Kathy took him to Disney World while Larry stayed at Barbara's house. Also, once a week Barbara watched Larry while Kathy and Peter went out for dinner. Larry's group home placement left a scar on Peter. He was afraid that since Kathy had already sent Larry away, she would send him away too if he did not behave. Although Kathy tried to reassure him that this would never happen Peter still felt that there was a limit and it possibility that his mother would send him away.
Kathy always knew that she did not want to sacrifice her and Peter's lives in order to raise Larry at home. She taught Peter that he was an important individual who had his own life. After Larry was diagnosed with autism, Peter got involved in a sibling workshop where they taught him how to interact and play with his brother. Peter did try everything with Larry that he had been told at the workshop. Initially, Larry was not happy that his brother was trying to play beside him but eventually accepted Peter's presence and the two of them learned to spend time together. Later on this proved to be a great help for Kathy. Larry always listened to Peter much better than to anyone else.

A. But if I was having trouble with Larry, he'd listen to Peter. He'd give me a hard time. (chuckle) Peter would come home and I'd say: "Peter, do something he's driving me crazy today". And he'd do what Peter'd say. "Come on Larry, you're gonna come upstairs!". And they would watch Much Music or put on some videos or music. I don't no what it was. I'd go up there just to see what was going on, and they're listening to some heavy metal group on the stereo up in their room. He's sitting on the edge of the bed just contentedly being there with Peter while looking through some comic books or something. And yet he was giving me a bad time. And yeah, they always liked to watch the Power Hour together. Or Much Music. He likes all kind of music, but he still likes that heavy metal stuff. And he does what Peter says.

Kathy and Peter had a very open relationship. Sometimes Peter had to support his mother emotionally since there was nobody else to do it.

A. (...) I would come home (After dropping Larry off
at the group home.), you know, it's obvious I've been crying. So I just said: "Oh yeah, I wish things were different, I wish Larry could be with us, but he just cannot." And Peter understood, you know. He'd give me a hug and we talked about it and then we then decided "Oh, what are we gonna watch on TV? Let's make some popcorn!" We tried to, you know, cheer ourselves up.

Peter had to cope with a lot of extra responsibilities imposed on him by his brother's condition. He never resented that.

He was never ashamed of his brother and was very defensive if anybody seemed to have a problem with Larry. From looking at the family pictures, one can tell that Larry and Peter have always had a good relationship. In one of the pictures, they are having an afternoon nap together, and in another one the two of them are sitting tightly at the end of the slide in a playground. This later picture was taken on a weekend when Larry was suppose to be on parent relief but his mother and brother missed him so much that they had to go and visit him. Peter moved out of his mother's house a couple of years ago. Since then he has hardly seen Larry. This concerns Kathy who thinks that Peter should make some effort to keep in contact with his brother. On the other hand she feels that she was the one who taught Peter to be his own man. She still thinks that her sons have a great relationship and Peter deserves the credits for that.

Q. You talked about Peter. I missed one point.
A. You know, he was great when Larry was young, he
was great when Larry was little when we were all together. Not as much now. As I said, he's gone on to his adult life, he's 25. But he was a good kid.

Q. He had extra responsibilities, but you felt it wasn't bad for him. He totally accepted Larry and they had a good relationship.

A. He becomes very angry if people don't understand Larry or don't want Larry around. He's very angry: "That's my brother", very defensive around Larry. I have two feelings about Peter. I think that if he has those strong feelings 'where are you?' 'why are you not here sometimes when your brother's home?' Why doesn't he go and visit his brother or be more part of things? But that's not Peter. He's 25, he has other priorities, he's got his girlfriends, his social life, karaoke (chuckle) and his brother's not number one on the list right now. But he's very protective of him and loves him very much. And he cared for him a lot when we were all together and worked with him a lot. He really, he totally understands Larry. And Larry relates to him so well. Larry has never ever given Peter a difficult time. He always does what Peter says.

Q. That's very interesting.

A. Even now and when he was little. They relate well and they never have a conflict. It's a mystery to me why it should be but that's the way it is. You know, something is there that Larry remembers somewhere in his subconscious, the hours that he spent with Peter when he was little and that bondage is there. Whenever he sees Peter he runs and he always gives him a hug and rubs him under the chin and gives him a big smile and he's obviously glad to see his brother. Instant reaction. And Peter has caused that to happen by the way he cared for him. That doesn't happen automatically. It makes me very happy to see Larry react that way and that kind of guy thing together.
The discourse of "Falling Apart"

Just with the passage of time some of Kathy's yearnings are gone. She no longer wants to be a young wife with a husband and a little baby in a stroller. Her goals are totally different now than they were when Larry was born. She has learned to appreciate the healing effect of time but was also shocked to discover that time can bring out old scars too. She thought that things in her life had fallen into their place and she was able to deal with her divorce and Larry's autism without any major setback. She never stopped to think about how she was doing in the midst of it. It came to her as a total surprise that those years under tremendous anxiety and stress could come back to haunt her.

Q. I was wondering whether you had any after thoughts or anything that you remembered and you'd like to talk about after our first conversation?

A. Yes I do, actually. Some, not particularly about Larry. But, for example, you asked me a couple of times; how did I cope with that, how did I get through that. And I didn't even know what to say to you. Because nobody really ever asked me that before. Nobody seemed to care (chuckle) how I was coping as long as Larry was doing okay, you know. I never really thought about that, about how I coped with it. But it's interesting, that just .... Everything seemed fine back then, you know, when the kids were little and Larry was even going through all those bad things. I just seemed to get through it okay. But now, that Peter's living with his dad, and he's like 24 and a half, and Larry's in the group home and I don't have a lot less stress in my life, and some quiet time for myself.

Q. Uh hum. Uh hum.
A. And now my nerves are just a wreck. You know, I ended up going to a psychiatrist. And I just said: "You have to do something because I have to work and I'm a mess! I cannot work you know." He feels it's delayed stress syndrome. And I, I said: "But you know, I didn't have any stress. Everything was fine. I had my parents supporting me and the kids are fine. Everything worked out fine. And he said: "You didn't feel it then, you're feeling it now. Because now everything is done and you have time to feel it." It's seems a little strange to me (chuckle), but that's what he said.

Q. And what do you mean you cannot work or how do you feel?

A. I couldn't, I reached the stage when I couldn't make a decision. Like I would begin to dress in the morning but I couldn't figure it out what to wear. I could wear this or I could wear that, I don't know. Then I would go to leave, and I would think: "What am I gonna do? Am I gonna drive to the subway or am I gonna go to Richmond Hill, am I gonna get on the train? I should've left and I don't know which way I'm gonna go." And I'm like paralyzed, just cannot decide what to do, even the simple little things. 'Am I gonna make a lunch? Am I gonna buy a lunch?' Everything, I just couldn't decide. And so the only reason I was okay for a while because at work it gets so busy and when we're extremely busy, my boss just says: "Okay. Here's what you do first, and here's what you do second, and then you can have lunch. Don't go to lunch until you have done that." And everything is so clear. And there's no decision to be made.

Q. Uh hum. Uh hum.

A. You just sit there and work. And so that was fine. Then when I got to my personal life, I couldn't even grocery shop. I didn't know what to buy. You know, I couldn't decide what to buy. And this is what prompted me to go to the doctor. And I said: "You know, this is crazy. It's no big decision when I go to the grocery store. Am I gonna have chicken, am I gonna have roast beef. What is it? Buy both. It doesn't matter. And I'm like having a fit to decide. I'm getting all upset, you
know." So anyway. He says it's typical of the anxiety that you feel. And when nothing's wrong, nothing's wrong.

Q. When did you start experiencing that ...?

A. Well, it was in November, 1996. He put me on some medication because I just couldn't cope with it anymore.

Q. But I guess, it came on gradually.

A. Yes, it came on gradually and then you find ways of dealing with stress. And I thought I was doing okay and then all of my self-help things quit working. (...) And I was just basically paralyzed, except at work where that was okay. But it was just ridiculous. And I had, you know I wasn't just willing to be like that. You know, I have things to do, I've got to get on with whatever .... Whatever I want to do in life, I cannot be paralyzed like that.

Q. Sure. And it's very good that you realized that right away. And you're better now? You don't have that problem?

A. No. He said, you know, he wants me to stay on the medicine for six months to a year and then he'll take me off. He says, that's enough to brake the cycle and help to, you know, get over it.

Perhaps Kathy needs to learn how to live her own life without ongoing parenting responsibilities. With her boys living away, there is a new challenge for Kathy to adjust to her new situation. It seems as if she has to newly require the skills necessary to live independently.
The discourse of "Maturation as a Parent"

Autism is such a mysterious condition. Kathy has often been puzzled by Larry's behaviours. Although occasionally she is frustrated by his unpredictability and the way it effects her life, she is able to accept him as he is. That was a gradual process throughout which Kathy as a mother matured. There are several factors that contributed to this process. First of all, Larry was very much a wanted child. His diagnosis was obtained at a young age which did not leave his mother in limbo for many years in terms of his potentials. Despite that, Kathy still had to learn to have realistic expectations of her son. She was able to listen to advice offered by professionals. The advice that guided her through the process of accepting Larry were explicit, short and never left room for interpretation.

A. (....) I think it's very important from the parts of the teachers, therapist or any of the care givers to be really blunt. The lady that came to my house every Monday, she asked me: "What do you want to work on first, what are your goals with Larry?" I said: "Well, I'd like him to get himself dressed in the morning." She said: "That's too big of a goal and that's too much into the future. He may never be able to do it. Why don't we think about getting Larry to put on his shirt." And even that took twelve steps. And he did eleven. And that took a long time. And she said: "You have to change your goals for him. Getting himself dressed may be ten or fifteen years away not months." But it helped me that she was very blunt and didn't let me have unrealistic goals because that's just disappointing. It brings you down, but it brings you down for one day, and then you realize you just have to change what you want and then you're okay, you're on track. It's better than going on year after year toward
a goal and never reach it.

Q. Don't you think that it helped you to accept Larry as he is.

A. Yes. And also the doctor at the hospital who was part of the diagnosing team, he said it very kindly that I would just have to learn how to accept Larry for what he is and to enjoy his little accomplishments as they arise. And to not have any expectations but to have pleasant surprises on the way. My mother didn't like him. She thought he was too much of a downer and he'd already written the whole book about Larry. That he'd already written him off. And I didn't take it that way. I took it that he wanted us to respect Larry and enjoy his accomplishments and not be continually daily disappointed that he wasn't normal because that's not good for him or for us. I have had some really good advise. But it's blunt. Just say what it is and I'm sorry but the parents have to get used to it. It's kinder.

Kathy was open to any input and listened with an affirmative attitude. She wanted things to work. In the meantime she had to remind herself to concentrate on the positives and not keep track of the negatives. Accepting children with autism is never a finished process since their needs and behaviours keep changing. This is also true for normally developing children but the changes their development displays are considered to be normal. Many times people with autism exhibit a discrepancy between their mental age and their chronological age. This certainly presents a challenge for parents. Kathy had learned to deal with Larry when he was a young child with autism. Now she has to manage a young man with autism who's interest does not differ a lot from when he was a three year old but certainly his size does. Kathy
acknowledges that the things that Larry gets pleasure from, like watching Sesame Street, is very different from what other 18 year olds enjoy. She does not hesitate to put his favourite videos on which are all geared for preschoolers. She does not attempt to make him happy with activities that would go beyond his mental abilities just for the sake of age appropriateness. Kathy does not want to pretend that Larry is able to do things that people of his generation can do. On the other hand, Kathy is very concerned that Larry should always dress his age and should look like any other teenager. She also wants him to learn socially acceptable behaviour so he does not do inappropriate things in public. Kathy has made peace with the fact that Larry has autism and that it is a life long condition. She is very realistic and does not hope for a miracle that would cure her son. Unlike her, Kathy's father is stuck at the grieving stage as he has not been able to get over his sorrow over Larry.

A. (...) My dad reads the National Enquirer too much. Like this hearing aid therapy. Come on, he's not deaf. Oh, but they put this white sound in there, some white sound therapy. This's been written up in all the tabloids and my dad thinks that it's gonna make all the difference in the world. And he gets really deflated when I tell him no, and 'besides dad if at 18 they've found some magical cure that would totally cure his autism, you still have an 18 year old boy who has not learned anything. He's never going to be normal. He cannot pick up at 18 years of age at a two year old level and ever be normal. It won't happen.' He doesn't like it, he thinks I'm pessimistic. But I'm not really. I'm not pessimistic at all.
Larry's condition has created some long term effects on Kathy's life as well. When she is trying to glance into her future she can see a lot of uncertainty. She used to have that picture that she would remarry and when retirement would come she would walk with her husband hand in hand along the beach somewhere in Florida. Now she is certain that this dream will never be realized. Even her retirement is uncertain. Since she was having so many financial difficulties when her boys were living with her it had never occurred to her to save money for her retirement. This uncertainty worries her a lot.

Kathy used to think that most people's life were perfect compare to hers. She is not so quick to think that way now. Sometimes she has even felt victory.

Q. I haven't asked you about real achievements, things that you as a person feel proud of, not just what you've achieved with Larry but things that you were able to deal with regarding him.

A. Yeah, yeah. When they were younger, I didn't feel, you know, that I was getting anywhere or accomplishing anything. It was just kind of making it from day to day and getting through. As I said, you know, I seemed to be okay. We were getting by, everything was all right. And then I heard a couple of instances like for example that one man, that I know, his wife left and he had a 4 year old daughter, she left the daughter. And he gave the child to his parents to raise. And I said: "Why? What's the problem?" And he said: "I cannot possibly raise a child and work full time." You know, things like this made me realize; Well, why cannot he? I can work full time and raise two kids and one of them has a real problem and I'm still here to talk about it.

Q. That's right.
A. So maybe what I'm doing is pretty good compared to this guy who wouldn't even try. I had a friend at work who had two little boys. And when her marriage split up she left them with her husband. And she just said: "I'm not getting into that. No way I'm going to try to work full time and raise two kids. He got the money, he can hire a nanny for the kids. I'll visit them on weekends, that's fine for me." And they still live with their father. And you know, through few things like that I've heard that people would not even tackle the job the first place. And I thought, you know ... Never occurred to me not to do it and then I did okay. I mean I have ... I didn't have to go on welfare or get assistance. I ended up, you know, going to night school and getting my certificate.

Getting her certificate exemplifies another lesson Kathy has learned as mother of a child with autism. Originally she had signed up for her night school when Larry was three years old. Around that time Larry started seizing which took Kathy's focus off from her studies. She made the decision that taking care of Larry was her first priority at that point in her life and put studying aside. Ten years later she did graduate from her night school with the additional knowledge to learn to postpone things until it is a better time to do them. Also, Kathy has learned to appreciate the little kind acts that have a positive effect on other people's life.

A. (...) But when you think about, when I was really having problems and somebody would do some little thing for me, that meant nothing to them. But to me at the receiving end it made that huge difference. And you can have that effect on people just by some little thing that you do. That's really, it's almost scary, you know, to think of the number of times that you don't do something for someone and you could and it would make a
big difference.

The lesson that Kathy values most has been the hardest to learn. The process of internalizing this lesson ran parallel with the process of accepting Larry's autism.

A. (...) I think when you raise a child like Larry, he teaches me more than I will ever teach him. I'm not a very patient person but I learned how to be patient with Larry. I always wanted to happen everything instantly. But I've learned that some goals are long term and I've settled down and I've become less impatient, less frustrated. That's a good thing to learn. I'm surprised I ever did it. That is not the way I was.

Q. That is a very hard lesson to learn.

A. But I'm more comfortable now because to be continually frustrated or anxious, wanting things and being like driven it's not comfortable. I'm just more comfortable and contented and satisfied with my life and with the way things go, the speed at which things happen. I'm not frustrated by which things happen. That's good experience for me. Took a long time (chuckle) to learn.
CHAPTER FOUR

REFLECTIVE ANALYSIS

The purpose of this chapter is to analyze whether the literature discussed in chapter one can provide an adequate framework to help us understand what Kathy’s story conveys. Also, an attempt will be made to validate the themes suggested in the current literature and describe new ones based on the data of this case study.

The responsibilities of parenting a child with autism last a lifetime. Kathy does not seem to protest against that. By accepting her son’s autism, she has accepted the demands that his condition places on her life. Since Larry’s development in his first year seemed normal, Kathy was allowed to retain a joyful outlook for his future. Then there was a time of uncertainty as Larry’s emerging distressing symptoms coexisted with his seemingly normal responses. This ambiguous situation with conflicting expectations ended when the diagnosis was made. Hill’s ABCX model is applicable in that situation when Kathy had to mobilize her resources in order to solve the crisis situation. “A” was the diagnosis of autism. “B” was Kathy’s response as she went through the adaptive stages of denial, bargaining, anger,
depression, and reaching “C” acceptance. She did reach her acceptance remarkably early, which is indicated by her ability to discuss her son's strengths and weaknesses with relative ease. Non-acceptance would suggest that she was still in crisis (“X”) over his diagnosis. Kathy’s acceptance is manifested by her ability to collaborate with professionals to make realistic short and long-term plans for Larry, as well as pursuing personal interests, unrelated to her son. Although Kathy did come to terms with her son's diagnosis and mobilized herself to provide appropriate resources for him, signs of chronic sorrow appeared evident. Olshansky (1962) described this mourning experience of the parent of a child with a developmental disability as one in which there is never full recovery. Rather, there are periodic episodes of acute sorrow often triggered by major developmental milestones that reawaken painful feelings of loss. Although these adaptational stages could be applied to Kathy’s experiences it is still questionable to what extent the above mentioned stage model is accurate in describing her.

Based on the case study, one may conclude that Kathy is currently in a depressed state resulting from finding herself without a mission. Her older son has moved out, and Larry largely lives in a group home. Her mission for Larry and Peter is finished and her whole need to cope has been removed. In the past year she has been diagnosed with delayed stress syndrome. This is Kathy's newest challenge. She has suffered an emotional crash after sustaining her strength for so long. This is her first experience of being unable to cope with her life situation. Up
until now she has devoted her life to the needs of her sons. She has had very little experience paying attention to her own needs. She is aware of the need to look back in order to sort things out, to confront her feelings and to come away with a total understanding of the impact that those stressful years have left on her life.

As a young child, Larry was unresponsive socially, had a difficult temper, posed a great deal of care giving problems, and displayed repetitive behaviour. All of these caused a great deal of stress for Kathy. These very same stressors were described in the literature on family lifecycle. However, since Larry was placed at a group home in his latency, most of the findings that apply to adolescence and adulthood do not apply to Kathy's experiences. Since Larry lives in a group home, the care giving demands do not present themselves as great stressors anymore. The stages of lifecycle seem to be too simplistic for the complexity of her experiences.

Larry has displayed all of the main symptoms of autism, but for Kathy the hardest one to deal with was his lack of responsiveness. Kathy had to fight for Larry's affection, as he did not seem to acknowledge her in any recognizable way. For a long time it was really hard for her to find any evidence of his attachment to her. By the time Kathy could detect his "humanness" Larry was already ten years old. Ever since then, Kathy has felt rewarded by their relationship which gives her energy to cope with her son's autism.

Kathy used instrumental (teaching her son, having a worker
from Parents Helping Parents) and palliative (self-help activities, informal support) strategies to promote her acceptance of her son and to develop adaptive parenting responses appropriate to his needs. Kathy has taken an active role in teaching Larry basic skills and later on introducing leisure activities to him. By doing so this empowered her to implement changes in Larry’s life. Her approach to teaching is excellent. She is able to establish goals that are relevant to her son’s development and are reachable for him. She achieves these goals with perseverance, gentle forcefulness and a lot of empathetic understanding. Kathy’s parents proved to be the source of her most valuable informal support. Her parents, her best friend, and her colleagues were always there for her. Their support enabled Kathy to cope with the impact of Larry’s disability. We can see how Hammer’s (1983) social support model can be applied to Kathy’s experiences. The stressful life event, her son’s autism has been tempered by encouragements, assistance, feedback, and hands-on help in the completion of daily tasks by members of her informal support system. Another palliative strategy that Kathy practiced was to draw the line on the expectations of others that would be too energy consuming for her. Being an advocate for her son also helped Kathy to cope with certain situations. Her approach to advocating was and is not confrontational. She would like people to make arrangements to accommodate Larry. Although Kathy was able to access a variety of informal supports, there was one important coping strategy, relying on spousal support, that Kathy could not access. Although Kathy’s parents were always
there for her, they could not possibly replace the role of a partner. Indeed, Kathy’s father went through his own cycle of acceptance and may still be struggling to reach that stage. Vadasy (1986) notes that single parents of children with a disability experience greater stresses in their family system than parents in intact families.

Kathy is quite aware of her sacrifices. Having a child with autism limited her chances to remarry which she really had wished for. She had to make many small sacrifices along the way in order to adjust her life to Larry’s ever changing needs. Although she recognizes the positive impact her sacrifices have had on Larry, Kathy feels, that they came at a great cost in terms of her life. She also indicated her frustration that despite all of her suffering and her efforts, autism still exists and the struggle of parents of children with autism remains the same.

Looking back, the single most stressful event in Kathy's life with Larry was placing her son in the group home. Although she had known from very early on that she did not want to sacrifice her and Peter's lives, in order to keep Larry at home, sending him away was heartbreaking for her. This was made even more difficult because she had to place him in the group home prematurely as she was unable to care for him without the appropriate before and after-school program. Now Kathy is happy with her son's living arrangements. However, she is still angry about being forced into a situation without being mentally prepared. Formal services and program have been found to be
critical in successful maternal adaptation to a child with autism (Donovan, 1988). In the case of Larry’s group home placement, the services deemed necessary by Kathy were not available. That is why this experience was so stressful for her.

Kathy's hopes regarding Larry's future have changed a number of times. As her understanding of his condition crystallized, her hopes became more and more realistic. Her major fear was Larry's inability to recognize danger. As a result, Kathy has learned to employ a number of cautionary measures when she is with her son. Puberty has brought new worries as Larry's psychosexual development reached a new stage. Kathy is in the process of adapting to this new situation.

Kathy had to deal not only with her son’s autism, but with people’s reactions to his disability. It is quite true that families exist and operate in a broader framework (Konstrataraes, & Hamatidis, 1991) which has an impact on the way they cope with certain situations. Kathy used to experience distress over the reactions of other people to her son's behaviour. She has become accustomed to the fact that her son occasionally may display some troubling behaviour in public, and does not get upset when it occurs.

Although Larry needed constant attention, Kathy tried her best to attend to Peter's needs as well. Her concern that she might not meet Peter’s needs was an additional stressor for Kathy. Larry’s disability had a great impact on Peter’s life. Peter shared the anticipation and excitement of the arrival of his newborn brother. He also shared the grief and the pain that
accompanied his brother's autism. Peter was eager to establish a relationship with his brother. While doing so, he applied the same basic behavioural principles that were used by his mother. He had employed these principles with respect for his brother's developmental status and their relationship. This in turn provided him with a vehicle for relating to his brother and also relieved his mother of some small portion of child care. Kathy is upset that since Peter has moved out he is not making any effort to spend time with his brother. It is possible that at this point in time, as Peter has reached adulthood in his life cycle, he is only able to provide long-distance support for his brother.

Kathy has matured as a parent by accepting her son, by successfully managing her life in spite of her hardships, and by learning and applying the lessons her experiences with her son with autism have taught her.

Kathy has the admirable ability to look at things that happened in the past, that were considered tragedies at the time, and talk about them jokingly. Maybe this sense of humor has attributed to her capability to maintain a positive attitude. This is how she summarized retrospectively her life with her son with autism.

A. I guess a lot of it was that I really wanted him so much that it didn't matter what was wrong, that I would just wanted a baby and wanted to take care of my baby. (Every time when Kathy said the word: baby, her eyes lit up.) And whatever he was OK, because I really wanted that baby, you know (chuckle). And I have disappointments, but I don't know. I also have a lot of things that I'm proud of too. A lot of accomplishments.
And I've been very lucky, as far as help and getting assistance and that kind of things. Things have fallen together very, very well. And I haven't been left high and dry.

The rich qualitative data gathered from the interviews with Kathy allowed me to obtain some insight into one parent's life with her son with autism. As a teacher working with children with autism, I often wonder how their parents could possible cope with them at home. There are days when my students make way too much noise, and they do not respond to anything. By the end of those days I am ready to scream. Unlike their parents, I am only responsible for their education and physical well being for a limited time during the week. One of my recurring questions has been: How can these parents live with the special demands of their child's disability year after year?

These very same questions have been contemplated by many researchers. It has been suggested that parents of a child with a disability have to go through the grieving process in order to be capable to plan realistically for their family's future (Saligman & Darling, 1989, Witcher, 1989). Although Kathy did go through those adaptational stages very quickly, this framework did not seem to be her major way of coping and planning for her family's future. Rather, it was the first of many steps that she had to take in her road of successful coping.

The behavioural problems of children with autism, coupled with developmental delays and minimal parental reinforcement, results in considerable care taking stress (Holroyd & McArthur,
Families of children with autism report more stress than do families of children with mental handicaps or other psychiatric problems (Holroyd & McArthur, 1976). The framework suggested by Konstataraes and Hamatidis (1991) which is the combination of the ABCX and the social ecology model allows us to examine all of the possible components of stress in a family's life with a child with a severe disability. It seems to accurately describe the ever changing demands placed on Kathy, her coping strategies that helped her avoid crisis, for the most part and the importance of external supports. Whereas the adaptational model is an appropriate model to explain the emotional response to having a child with a severe disability, it does not address the other stressors that parents have to face, nor does it suggest interventions.

In their attempt to prevent, avoid, or control their emotional distress parents of children with disability use palliative and instrumental coping strategies (Harris et al., 1991). Kathy did employ most of those strategies, however, as a single mother she was unable to rely on a supportive partner. It is important to emphasize the role of social support which can enhance successful maternal coping (Hammer, 1983). Social support was the major factor in Kathy's successful maternal adaptation.

Autism is such a puzzling disability. The construct of "theory of mind" which refers to our understanding of the feelings, beliefs, and desires of others may be a useful
framework to gain a better understanding of this handicapping condition and of the stress and coping strategies of parents of children with a severe disability. This construct has allowed researchers to identify the essence of autism as an impairment in the ability to recognize other people’s minds (Frith, 1989). This case study demonstrated Larry’s impaired ability to recognize his mother and brother’s mind. However, at age ten something significant happened. Could it be that Larry was all along learning to appreciate or recognize the minds of significant others, such as his mother, but Kathy was not equipped to read the possibly subtle signs of his affection? Kathy, like all mothers had particular expectations of what would be indicators of attachment and affection and these were based on the “normal” mother child relationship. Currently, Kathy and Larry have a relationship that Kathy finds satisfying. In order to appreciate her relationship with her son Kathy had to accept his ways of showing affection and learn to recognize them.

Besides validating the findings of the existing literature, three new themes were identified that could contribute to our understanding of the parenting experiences of a mother of a child with autism.

The first new theme is related to Kathy’s “empty nest” depression. When Peter leaves, and Larry is largely in a group home, she loses her mission, and her whole ability to self sustain falls apart. This emotional crash is very different from stage five in the literature on grieving and has not been documented in relation to parenting. This theme: “Falling apart”
underlines the need for a new type of support which could assist parents to cope with their new living arrangements when their child with a severe disability leaves home.

The second new theme is related to one of Kathy’s self preserving strategies. “Setting Limits” She is unable to meet the expectation from parents organizations to change the system. She cannot cope with the enormity of being a change agent, in addition to coping as a parent. Despite that, she consented to this study and devoted a lot of time and thought to it. She considered the act of telling her story as a way to reach out to other parents of children with autism and to share her experiences with them.

The third new theme is “Advocating”. Learning to be a vocal, strong advocate for herself and Larry is a major part of her coping, which has not been identified as a theme in the five stages of coping with grief.

These three new themes complement the validated themes from the current literature and could be part of a future conceptual framework of parental coping strategies.

Kathy’s experiences and coping strategies are in part due to her nature. There is no such thing as a typical child with autism. Consequently, each parent’s experiences with a child with autism is unique. This case study should be viewed and valued based on this information.

As I sat across from Kathy, for our final discussion, I was struck by the commitment and love that she possesses for her son. I admired her persistence, her accepting nature and her ability
to look at the bright side of things. Also, I felt very privileged that she had shared her experiences freely and openly with me.
REFERENCES


Letter of consent

I agree to participate in the study of Retrospective experiences of families of adolescents children with autism.

I understand the requirements of my involvement in this study. I am aware, that I may withdraw at any time and request that any information collected to that point be discarded.

Signature:________________

Date: Toronto, ____________
APPENDIX II

1. Diagnosis

* uncertainty before the diagnosis
* circumstances around the diagnosis
* fighting for a label
* why does he have autism

2. Encountering autism

* Non-responsiveness
* behavioural problems
* attachment
* impaired theory of mind
* grieving
* feeling united

3. Fruitless sacrifices?

* fruitless sacrifices
* missing out on things

4. Day-to-day living/Stress and Coping

* getting through the day
* self-help activities
* financial problems
* informal support
* formal support
* living arrangements
* advocating
* self-preservation

5. Getting adequate treatment

* group home
* medical care
* schools
6. Mother as teacher

* teaching basic skills
* discouragements
* introducing leisure activities
* taking pride in his accomplishments
* being open to new approaches

7. Hopes and fears

* changing hopes
* constant fear for his physical safety
* worries after puberty

8. Social reactions

* acceptance by family and strangers
* feeling stigmatized
* people can be helpful too

9. The other child

* meeting his needs
* sibling's extra responsibilities
* brothers with a strong relationship

10. Falling apart

* emotional crash
* treatment

11. Maturation as a parent

* accepting the child
* long term effects
* victories
* lessons learned from this experience