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THE EXPERIENCES OF MOTHERS AND FATHERS OVER TIME IN PARENTING A CHILD WITH AUTHISM

BY

SUSAN ELIZABETH FOLEY ©

A THESIS SUBMITTED TO THE FACULTY OF GRADUATE
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ABSTRACT

The purpose of this study was to understand the experiences of mothers and fathers over time in dealing with autism. There is evidence that there are specific characteristics associated with autism that may contribute to unique challenges for parents. Since few theories exist to describe the experiences of parents in managing a child with autism, an exploratory method of inquiry was chosen. The researcher examined parental accounts of their experiences by using a grounded theory approach. Open-ended interviews were conducted with mothers and fathers at various stages of the process of raising their children. The process of data collection and analysis involved the constant comparative method of analysis in order to determine the appropriate data to collect next in order to assist in the development of the emerging theory. The data illustrated a process in raising a child with autism which emerged into a sequence of six stages: Expecting Normal, Worrying about Differences, Needing to Know, Having it Real, Taking Action, and Going Beyond Autism. Over time, parents were involved in a process of reframing both the vision of their children as well as the vision of family life, which involved changing previous expectations to fit the reality of their child's limitations and behaviours. The process of reframing the vision of family involved making adjustments so that the family's life was more congruent with the vision that they had regarding what families should look like.

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I would like to acknowledge the eight participants who so willingly welcomed me into their homes to openly discuss their experiences in parenting children with autism. I recognize the difficulty that many of them faced in reliving their early experiences and thank them for being so generous in their participation. Without them, this study could not have been completed.

Finally, to my family and friends I express a special thanks for both the emotional and financial support that you provided throughout this project. All have been a constant source of motivation and support. I could never have done this without *you.*

TABLE OF CONTENTS

I. INTRODUCTION

A great deal of attention has been devoted to the experience of parenthood (Gable, Belsky, & Crnic, 1992; Goldberg & Easterbrooks, 1984; Jenkins & Smith, 1991; Lamb, Pleck, & Levine, 1986). Mothers and fathers often look forward to the experience with great anticipation and numerous expectations. Among the many expectations are concerns related to the health, success, and happiness of the new child. Most families, however, are not expecting to be faced with the task of raising a child with special needs. Therefore, to learn either at birth or later that a child has special needs is often a tremendous shock to parents. The literature with respect to the ways that parents manage this oftentimes overwhelming change remains limited.

Focus on the process that parents of children with disabilities experience has been relatively limited. A better understanding of some of the issues that such families experience will increase our capacity to assist mothers and fathers over time. Previous research in relation to parents of children with disabilities has tended to focus on processes such as grief and sorrow (Adams, Wilgosh, & Sobsey, 1990). As well, much of our understanding of the experiences of this population of parents is based on literature that focuses on the numerous stresses that parents confront when there is a child with a disability in the family (Donovan, 1988). The effects of such stresses and the ways that they are managed over time is an area that has received considerably less attention. A minority of researchers in the area of disabilities are beginning to recognize the need for research which addresses the ways that parents manage stress and cope with the various challenges associated with disabilities (Adams et al., 1990; Scorgie, Wilgosh, & McDonald, 1996).

Understanding parental experiences particular to disabilities and their stresses and challenges is necessary to be able to effectively assist such families in dealing with their situation. The literature that does exist tends to group multiple disabilities in examining this issue. For example, Frey, Greenberg, and Fewell (1989) examined such disabilities as Down's syndrome, cerebral palsy, multiple sensory handicaps, William's syndrome, and trisomy-19. The problem with grouping disabilities in research studies is that in doing so, we are failing to recognize the uniqueness that each individual disability has in terms of onset, course, and outcome. It is for this reason that there is a serious need for in-depth, theory-building research focusing on specific disabilities and how parents experience and deal with them over time.

The specific disability that was the focus of this research is autism. Families of children with autism tend to be faced with issues and concerns that families of children with other disabilities do not. Unlike other disabilities, which are typically present at birth and are generally physically visible, autism is not always immediately noticeable to parents or health care professionals. For this reason, parents of children with autism often struggle with issues related to the detection and diagnosis of the disability (Zoltak, 1986). Oftentimes, the symptoms of autism are accidentally overlooked or misunderstood and as a result, there may either be a delay in diagnosis or misdiagnosis (Siegel, Pliner, Eschler, & Elliot, 1988).

In the years following diagnosis, parents of children with autism may experience frustration, worry, or sadness. The lack of independence of children with autism, even in their adult years, can be disconcerting for many parents. A large percentage of children with autism will require assistance for the remainder of their lives. This may mean a lifetime of caregiving for the child and the added stress of wondering what will happen to the child once parents die (Adams et al., 1990; Mengel, Marcus, & Dunkle, 1996). Ambiguity exists with respect to when the role of parenthood ends. Research is needed to determine how parents experience this ongoing role in order to better assist them in dealing with issues that may arise in later life as both the child and the parents get older.

Statement of Purpose

The purpose of this research was to understand what parents experience over time in raising a child with autism. This research examined parental accounts of their experiences and attempted to understand the process that such parents experience. By speaking to parents about what raising a child with autism has been like, this research attempted to obtain a more complete picture of this particular disability and how it is experienced.

II. SURVEY OF THE LITERATURE

According to the DSM-IV, autism has an incidence of approximately 2-5 cases per 10,000 individuals (American Psychiatric Association, 1994). Autism is a disorder of social interaction and communication. The DSM-IV recognizes among the symptoms of autism: (1) impairment in the use of nonverbal behaviours that regulate social interaction; (2) failure to develop relationships with peers at the appropriate developmental level; (3) a lack of spontaneous seeking to share enjoyment and interests with other people; (4) a lack of social or emotional reciprocity; (5) delay or lack of the development of language; (6) inability to initiate or sustain a conversation with others; (7) repetitive use of language; (8) lack of play abilities appropriate to developmental level; and (9) repetitive and stereotyped patterns of behaviour, interests, and activities (American Psychiatric Association, 1994). Autism is an unpredictable and pervasive developmental disorder that presents significant challenges to parents in terms of management of the disability.

In order to better understand some of the issues particular to parents of children with autism, three main bodies of literature were reviewed. The first focused on the impact on parents in general in terms of the numerous behavioural challenges associated with autism. Also, gender differences were reviewed with respect to how mothers and fathers may differ in their experience with this disability. Lastly, particular issues that tend to be of concern in dealing with autism were examined. The above bodies of literature supported the notion that autism is indeed a unique disability when compared with other chronic, childhood disabilities. As such, it is necessary to pursue research which addresses specifically the management of autism.

Parenting a Child with Autism

How parents manage when caring for a child with a disability has come under scrutiny by researchers in recent years. Certain disabilities represent a unique developmental course and as such, may present potential challenges and stressors uncommon to other disabilities. One such disability is autism.

There are numerous articles that focus on the enormous amount of stress that these parents experience (Bristol & Schopler, 1983; DeMyer & Goldberg, 1983; Gray, 1994; Milgram & Atzil, 1988; Moes, Koegel, Schreibman, & Loos, 1992; Wolf, Noh, Fisman, & Speechley, 1989). In order to begin to understand how parenting stress related to autism may develop, it is essential to review some of the behavioural characteristics that may contribute to such stress. Such characteristics include uneven intellectual development, disruptive behaviour, and reaction to changes in routine. The following sections will include descriptions of these behavioural characteristics.

1) Uneven Intellectual Development

Parents of children with autism often face confusion with respect to the capabilities of their children. Since there are no standardized diagnostic instruments specifically for autism, tests of cognitive functioning are often used. As a result, children may receive a dual diagnosis of both autism and mental retardation (Moes, 1995). According to Ritvo and Freeman (1978) the confusion often arises for parents when their child's development seems somewhat uneven. For example, children with autism typically perform poorly on some tests (typically verbal tests) and relatively well on others (typically nonverbal tests) (Ritvo & Freeman, 1978). The mental retardation label does not seem applicable across all situations and parents often find this confusing since they may not know what to expect in terms of their child's capabilities.

The discrepancy in capabilities has been defined as splinter effects. Such effects refer to specialized skills that are often present in children with autism. Children with autism often have knowledge which is age-appropriate, but only in certain areas. For example, a child with autism might know definitions of complex words, but might not be able to effectively communicate his/her daily needs (Norton & Drew, 1994). Understanding splinter effects can be both confusing and stressful for parents. Furthermore, "this wide divergence in ability levels often promotes much greater expectations than the child is able to deliver and leads to high levels of frustration for both parents and child" (Norton & Drew, 1994, p.71).

2) Disruptive Behaviour

Disruptive behaviour of children with autism is another aspect of behaviour with the potential to produce parenting stress. It is not uncommon for children with autism to exhibit disruptive behaviour that is often very difficult to manage such as: self-stimulation, self-injury, aggression, tantrums, property destruction, and erratic sleep behaviour (Moes, 1995; Norton & Drew, 1994).

Self-stimulation is a common behaviour for children with autism. Typically, self-stimulation is defined as repetitive or stereotypic behaviour that serves no apparent purpose (Moes, 1995). Examples of self-stimulatory behaviour might include rocking, hand flapping, or gazing at lights. It is a means for children with autism to receive and/or reduce sensory input from the environment. However, observing such behaviours can often be disturbing for parents, especially since the majority of children engaging in self-stimulatory behaviours may do so for most of their waking hours (Schreibman, Koegel, & Koegel, 1989).

Maybe the most dramatic and problematic disruptive behaviour that children with autism may tend to exhibit is self-injury. Moes(1995) describes self-injurious behaviours as any behaviours inflicting physical damaging to an individual's body. Examples would include head-banging and self-hitting. As with most behaviours, the severity of this behaviour can vary and at its extreme, can result in serious injuries to the child (Schreibman, 1988). Obviously, for parents to watch their children engage in behaviours that are harmful may be extremely stressful as few parents like to see their children get hurt.

"Other disruptive behaviours such as aggression, tantrums, and property destruction tend to occur in varying degrees in children with autism" (Moes, 1995, p.84). However, as with the former disruptive behaviours, these too have the potential to be extremely troubling to both mothers and fathers.

Not only may the occurrence of disruptive behaviours produce stress because many of them are difficult for parents to watch, they can produce stress in other ways. For example, as a result of engaging in disruptive behaviours children tend to be stigmatized by adults as well as other children. Parents may struggle with this stigmatization and experience stress as a result of worrying about their child and the possibility that he/she may never fit into society like other children. As well, disruptive behaviours may produce stress since parents often do not know how to handle them appropriately and may feel inadequate as a result. Lastly, some disruptive behaviours can produce stress simply due to their unpredictability. Parents may feel uncomfortable as a result of being unsure as to when and where such behaviours will occur.

3) Changes in Routine

Commonly children with autism tend to prefer constancy in their lives, especially with respect to maintaining the same routines from day to day (Moes, 1995). Deviations from regular routines can cause great difficulty for parents or other caregivers. Parents or caregivers may find themselves faced with tantrums or aggression as a result of a change in routine (Moes, 1995).

"Accompanying the desire for sameness comes a tendency to be continually frightened of harmless things, while seeming oblivious to actual threats and dangers" (Moes, 1995, p. 84). The above effects that can result from change in routine can be challenging and difficult for parents to deal with. Not only do parents need to learn to follow a routine as closely as possible, they also have to learn the necessary skills to prepare their child for changes in that routine when applicable. Furthermore, like disruptive behaviours, unpredictable behaviours as a result of the need for sameness can lead to negative reactions from the general public who may see the child's behaviour as inappropriate, but may not realize that such behaviours are a part of the disability.

Clearly, there are various behavioural characteristics associated with autism that have the potential to produce stress in parents. With the realization that parents struggle to keep maladaptive behaviours under control, there has been some emphasis of late on understanding how parent education programs may assist parents in feeling in control and alleviating sources of stress related to behavioural concerns (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Campbell, Schopler, Cueva, & Hallin, 1996). Moes (1995) suggests that for parents needing meaningful changes in the lives of both themselves and their children with disabilities, interventions that teach parenting skills that can be applied to daily routines can produce widespread progress and reduce parenting stress. Other researchers have focused on understanding the interaction among a family's resources, coping skills, and their appraisal of the stressor to determine how families respond to stress (Bristol, 1987; Willoughby & Glidden, 1995). It has been suggested that coping skills are a useful supplement to parent education initiatives (Moes, 1995).

Parental Experiences of Stress

While we have reviewed various characteristics of autism that may lead to stress in parents, there is some research which addresses how parents experience such stress (Bristol & Schopler, 1983; DeMyer & Goldberg, 1983; Gray, 1994; Milgram & Atzil, 1988; Moes et al., 1992; Wolf et al., 1989). However, with respect to the above studies, Byrne and Cunningham (1985) point to the lack of a clear definition of stress as a methodological issue which needs to be addressed in future research. The concept of stress is often used without explicit definition and this results in a lack of consistency across studies.

The most common way that stress experiences are examined is through the use of self-report instruments which measure the amount of stress in families. Wolf et al. (1989) used in their sample children with autism, Down's syndrome, and developmentally-average children. Parents completed the Parenting Stress Index (Loyd & Abidin, 1985) and the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). Parents of children with autism had significantly higher scores than those of either of the other two control groups. Furthermore, mothers and fathers within all samples reported similar amounts of stress.

Morgan (1988) reports that in studies comparing parents of children with autism with parents of non-handicapped children or children with other handicaps, consistent results have not always been obtained. Some studies provide evidence that stress for parents is related to specific anxiety producing events (Koegel, Schreibman, O'Neill, & Burke, 1983), while others suggest that there is a specific stress reaction associated with autism (Bristol, 1984). Furthermore, some research finds no differences in stress levels between parents of children with autism and families without a disabled member (Koegel et al., 1983) while other studies finds differences in this respect (Holroyd & McArthur, 1976; Wolf et al., 1989).

Koegel et al. (1983) studied various aspects of parental functioning in mothers and fathers of children with autism. Earlier research suggests that multiple measures of family adjustment assist in the understanding of the general stress levels of parents (Hafner, Butcher, Hall, & Quast, 1969). Koegel et al. (1983) found that "on the MMPI, these parents scored within the normal range and did not differ from a comparison group of families with only normal children; on the Dyadic Adjustment Scale (Spanier, 1976), which assesses marital adjustment, they produced scores similar to a normative group of happily married couples; on the Family Environment Scale (Moos, Insel, & Humphrey, 1974), which assesses interpersonal relationships among family members, their scores on the 10 subscales did not differ significantly from the normative group scores" (Morgan, 1988, p.267). As a result, Koegel et al. (1983) concluded that their results failed to provide support for a general stress reaction by parents to an autistic child. Rather, parental stress may be highly situational and specific to anxiety-producing situations.

Holroyd and McArthur (1976) examined mothers' reports of stress when raising children with autism, Down's syndrome, and children being seen in an outpatient psychiatric clinic. While mothers of children with autism reported more problems than other mothers, there were still various problems that these mothers shared with mothers of children with Down's syndrome. Common problems included poor health, depressed mood, inordinate time demands, excessive dependence of their children on them, pessimism in relation to their child's future, and limits with respect to family opportunity. However, in relation to behavioural issues, mothers of children with autism reported more disappointment and embarrassment with respect to taking the child to public places. Also, mothers of children with autism reported their children as being more physically dependent on them for care. Lastly, children with autism were viewed as having more difficult personality characteristics and were seen as more disruptive of family activities.

Bristol (1984) reported on the ways that stress changes in relation to autism as the child and parent age. Initial stresses revolved around the negative impact of the child on the family and evolved to include concerns in relation to the ability of the child to survive in the community. As children grew older, concerns changed and included developmental aspects such as masturbation, self-care in menstruation, and fear of pregnancy. In addition, parents of children with autism reported that as their children grew older tolerance of the community with respect to deviant behaviour tended to diminish. Unlike Koegel et al. (1983), this study seemed to point to a characteristic profile of stress associated with parenting a child with autism. This finding could be partially attributed to the fact that Koegel et al.'s (1983) research represents a more comprehensive, better controlled study than Bristol (1984).

Some researchers have acknowledged that parental stress that persists over time has the potential to lead to burnout (Bristol & Schopler, 1983; Marcus, 1984). Marcus (1984), in a study of chronically handicapped children, identified stressors contributing to burnout as problems obtaining diagnosis, difficulty accessing services, isolation resulting from having a child whose behaviours set the family apart, lack of support, and parental neglect of their own personal and social needs.

Although a great deal of attention has been devoted to understanding stress, the lack of consistent findings related to stress and differences between stress levels of various populations does not allow us to draw any firm conclusions regarding which families are subject to high levels of stress and which are not (Byrne & Cunningham, 1985). However, the evidence seems to point to the fact that families of children with autism experience increased levels of stress as a result of various characteristics of the disability. Further research is needed to determine exactly how autism impacts parents. As well, since the experience of stress may be only one aspect of the experiences of parents when parenting a child with autism, additional research is needed to determine the entire nature of parents' experiences.

Gender Differences in Parenting a Child with Autism

It seems naive to assume that all parents experience autism in the same way or that parents of different genders experience autism identically. Following is a review that focuses on research to date that has examined the ways that mothers and fathers differ in terms of their experience of autism and their roles in caregiving. Research focusing on gender differences is relatively new and much more needs to be completed in this area.

Traditionally, in studies examining parental experiences, samples have comprised mainly mothers. As a result, the literature remains relatively one-sided. It is important to include fathers in samples whenever possible since accounts of their experiences are equally valuable and will assist in our understanding of what both members of a couple experience. A more complete understanding of some of the interactions that exist between couples will provide us with valuable information regarding family dynamics. Furthermore, until recently gender differences in parenting experiences were rarely explored with varying disabilities. As a result, our understanding of gender issues is relatively limited with respect to autism.

1) Mothers of Children with Autism

Research has found that mothers of children with autism are primarily responsible for caregiving. Holmes and Carr (1991) used in their sample parents of adults with both Down's syndrome and autism. They found that for all physical care tasks except eating, mothers assisted the disabled family member almost entirely unaided in over half of the cases. In the situations in which mothers were receiving assistance it was fathers and siblings who were helping. Assistance from other family members tended to be in the form of supervision, rather than physical care or domestic tasks. Other studies focusing on autism have found similar results (DeMyer, 1979; Morgan, 1988; Willoughby & Glidden, 1995). Traditionally, mothers have been the family member responsible for staying at home to attend to the child's needs, while fathers are generally employed full-time. A similar pattern has been found in families of children with autism.

While the above caregiving pattern may be similar for mothers of children with other disabilities as well as mothers of children of developmentally normal children, researchers have also found aspects of caregiving that are particular to mothers of autism. For example, DeMyer and Goldberg (1983) showed that mothers of young children with autism often find themselves overwhelmed because of unrelenting caregiving demands and concern for the physical welfare of their children who typically show little understanding of a sense of danger. Furthermore, DeMyer and Goldberg (1983) found that as children with autism grew older, the concerns of mothers shifted somewhat. Mothers' concerns tended to shift toward aspects such as self-help instruction and the management of behaviour in public places. In addition, some mothers also reported concern over their ability to manage behaviours such as physical aggression, especially in the adolescent years when their child increases in physical size and strength (DeMyer & Goldberg, 1983).

Behavioural and cognitive issues associated with autism seem to be areas that relate closely to the amount of stress that mothers may experience as a result of being full-time caregivers. In fact, stress is an aspect of caregiving for mothers that has been well documented in the literature (Adams et al., 1990; Moes et al., 1992). As a result of the level of dependency of their children, difficulty managing problem behaviours, and care across the life-span, mothers experience a great deal of stress (Moes, 1995). Milgram and Atzil (1988) found that for mothers who are primary caregivers, children's shortcomings are viewed as failures on their part.

Willoughby and Glidden (1995) found that stress can be partially alleviated by family members, particularly husbands, who participate in child care responsibilities and other household tasks. The tremendous burden of responsibility that many mothers experience can be lifted somewhat if other family members are willing to assist with caregiving responsibilities. Studies have found that parental roles in families of children with disabilities are generally more traditional than in families of children without disabilities (Cook, 1988). Even when women are employed outside the home, they do not receive greater assistance with household tasks than mothers who are not employed (Marcenko & Meyers, 1991; Willoughby & Glidden, 1995).

Statistics regarding the labour force participation of mothers of children with autism are conflicting. While some studies report mothers to be the family member who stays home full-time, other studies report that mothers are working in the paid labour force either part-time or full-time. Further research is needed to determine which is the case. As well, further research would assist in understanding other aspects of paternal support aside from caregiving responsibilities, which may be important to mothers.

2) Fathers of Children with Autism

While there has been a shift toward increased involvement of fathers in families in general, in the majority of cases mothers are still the primary caregivers. This same pattern of care has been found in families of children with autism. Milgram and Atzil (1988) found that fathers of children with autism assume more financial responsibilities outside the home than mothers, and as a result, are less available to assist with caregiving responsibilities. In this study, all fathers were employed outside the home.

Few studies actually ask fathers themselves to report how much they participate. Once again, results rely heavily on mothers' reports, with the exception of a few studies (Bristol, Gallagher, & Schopler, 1988; Gray, 1994; Midence & O'Neill, 1999; Milgram & Atzil, 1988; Willoughby & Glidden, 1995). Bristol et al. (1988), in a study of mothers and fathers of both developmentally disabled boys and non-disabled boys, found both groups of fathers to be involved in child care. This study found that fathers of non-disabled children shared almost equally with mothers in child care. Fathers of disabled children, however, did not support their wives nearly as much. Both mothers and fathers of developmentally disabled children reported that fathers assumed less responsibility in child care than did mothers and fathers of non-disabled children. Furthermore, fathers in families of disabled children also assumed less responsibility for general household tasks than did fathers in families of non-disabled children (Bristol et al., 1988).

Milgram and Atzil (1988), in a study of mothers and fathers of children with autism found similar results with respect to child care responsibilities. They examined parenting share, fairness, and satisfaction between mothers and fathers and found agreement between them to be quite high. Fathers reported that they do about one-third of the parental care of the child and mothers confirmed fathers' estimates by reporting independently that they themselves do about two-thirds of the child care. And "[s]ince mothers do far more than fathers in parenting, it is not surprising that mothers believe that they should do less, and fathers that they should do more" (Milgram & Atzil, 1988, p.421).

Willoughby and Glidden (1995), in a study of 48 married couples who were raising a child with a developmental disability, examined the division of child care. A list of eight tasks was used to measure the division of child care for each couple: feeding, changing diapers, dressing, bathing, getting ready for bed, getting up at night, playing, and helping with activities. Maternal work force participation was also measured and 10% of the mothers in the sample were employed full-time, 39% were employed part-time, and 51% were not employed outside the home. Findings indicated that fathers participated less in child care activity than mothers. "The only tasks in which the majority of fathers participated in close to 50% of the child care were those of play and helping with activities" (Willoughby & Glidden, 1995, p.402). These findings are supported by those of Holmes and Carr (1991) who found that when fathers participate in caregiving, it generally tends to be in the form of supervision of the child with autism, as opposed to participating in household tasks or physical care.

Research is pointing to the benefits for both parents when fathers spend more time in a parenting role (Baruch & Barnett, 1986; Bristol et al., 1988; Lamb et al., 1986; Willoughby & Glidden, 1995). Bristol et al. (1988) examined the relation between spousal support and aspects of adaptation such as depression, marital satisfaction, and observed parenting interactions. What they found is that it was not the actual support provided by the fathers that indicated how happy mothers were, but the discrepancy between actual support and the support that mothers thought they should be receiving. This study included parents of boys with autism and communication disorders who were between the ages of 2 and 6 years of age.

Willoughby and Glidden (1995) conducted a similar study using a broader sample of parents who were rearing at least one child who had or was at risk for developing a developmental disability. They found that greater participation in child care was associated with greater marital satisfaction for both parents of children with developmental disabilities. As Benson and Gross (1989) suggested, parents who work together to meet the needs of their children with developmental disabilities may in fact enhance their marriage in the process.

Most recently, qualitative research has begun to examine the experiences and coping strategies of both mothers and fathers parenting children with autism (Gray, 1994; Midence & O'Neill, 1999). Gray (1994) reported the most serious stresses faced by parents to be problems with the lack of normal language, disruptive and violent behaviour, inappropriate eating and toileting, and inappropriate sexual expression. As well, the grounded theory pilot study of Midence and O'Neill (1999) found six core categories describing the experiences of parents. These included parents' difficulties in understanding their child's behaviours as well as confusion resulting from parents' inability to make sense of these behaviours, and problems obtaining a diagnosis. In addition, the findings indicate that parents feel a sense of relief upon learning the diagnosis.

Although some researchers have begun to recognize the importance of understanding the experiences of parents of children with autism, the results with respect to how fathers' participation in the family is experienced remain limited. The minority of studies that have elicited data from fathers have reported results that focus more on what fathers physically do in the family when there is a child with autism. There is little research which examines how fathers experience raising a child with autism in terms of how they feel and how they are impacted.

One way to understand the experiences of mothers and fathers in raising a child with autism is to speak with both parents about their experiences, especially in light of the fact that more fathers are participating in tasks that in the past they have not. Current literature points to the need for the recognition that individual differences may occur in the reactions of parents to children with autism. What little we do know about the differences in the experiences of mothers and fathers of children with autism seems to point to the possibility that the genders experience things quite differently. Understanding such differences is key to developing intervention plans that can assist both mothers and fathers in dealing with the disability of their child.

The Process of Parenting a Child with Autism

Aside from behavioural issues that parents experience in dealing with a child with autism, there are certain other concerns that face parents over the life span. Autism represents for parents a unique developmental course. Over time, parents faced with raising a child with autism experience significant challenges which are different from those experienced by parents of children with other disabilities.

1) <u>Diagnosis</u>

The particular hardships that mothers and fathers of children with autism experience with respect to diagnosis have begun to be documented (Siegel et al., 1988; Zoltak, 1986). Although it is generally recognized that receiving a diagnosis for a child with autism is an ambiguous and often frustrating experience, little is known specifically about how parents manage this experience.

"Early recognition of ...[autism] requires prompt referral, diagnosis, and management" (Zoltak, 1986, p.90). With respect to diagnosis, however, promptness is not always clear cut since the diagnosis of autism is not well-defined. To begin, "symptoms of autism can be mistaken for other disorders, such as deafness, hyperactivity, emotional disturbance, language disorder, or mental retardation" (Siegel et al., 1988, p.199). Siegel et al. (1988) found an interval time of 13 months between the time parents first became concerned about their children's development and the time that an initial diagnosis was received. Furthermore, "a definitive diagnosis came about 2 years after the initial diagnosis" (Siegel et al., 1988, p.202).

Another reason that autism is difficult to diagnose is because the symptomology of this disability varies. "...[S]ome children are extremely withdrawn and have no language skills while others can function independently"

(Zoltak, 1986, p.90). Conversely, some children with autism experience this disorder early in infancy while others develop normally for the first year or two of life and then experience slower development (Zoltak, 1986). Both of the above factors can make it difficult for professionals to give a definitive diagnosis of autism. From a professional perspective, the fact that autism is not extremely common can make diagnosis difficult. In addition, the possibility exists that parents do not act upon concerns regarding their child's developmental delays, possibly because they are experiencing denial or do not recognize the seriousness of the situation.

2) Dependence of Children over Time

A second developmental concern that can be challenging for parents of children with autism is the dependence of their children over time. Parents hope that their children have the potential to achieve independence in adulthood (Mengel, Marcus, & Dunkle, 1996). However, for children with developmental disabilities such as autism, the reality is that they may be dependent on others throughout their lifetime. For slightly less than 10% of children with autism, there is the promise of doing very well in adult life, holding jobs, and maybe even having families (Gillberg, 1991). However, there is other research indicating that "...the vast majority of these children remain socially severely restricted as adults" (Gillberg, 1991, p.376). Approximately 60% of children with typical autism will grow up to be completely dependent on adults to care for them in all aspects of life (Gillberg, 1991).

Studies regarding the developmental functioning of children with autism over time seem to support the fact that outcomes for these children may not be promising in the majority of cases. To date, few studies have been completed that have begun to understand the concerns that parents experience as a result of the lack of independence of their children with autism and severe disabilities (Holmes & Carr, 1991; Adams et al., 1990).

One study that examined parental experiences in later life indicated that parents of individuals with autism report experiencing more difficulties since the child had grown up (Holmes & Carr, 1991). Holmes and Carr's (1991) sample was comprised of parents of adults with both Down's syndrome and autism. The authors were interested in determining whether caring became easier or harder as parents and the handicapped individual became older. They found that three-quarters of the parents of individuals with Down's syndrome thought that their son or daughter was less difficult to look after now that he/she had grown up. Conversely, only 37% of the parents of autistic individuals felt the same way. Parents of individuals with autism reported that "[t]hey had to deal with significantly more behaviour problems without the benefit of any regular, skilled professional advice" (Holmes & Carr, 1991, p. 174).

A second study exploring the experience of parents in caring for a child with severe disabilities found that parents reported issues relative to care over time (Adams et al., 1990). In describing their experiences, parents indicated deep concerns regarding the future of their child with severe disabilities. Specifically, mothers and fathers worry about what will happen to their child once they are no longer able to act as primary caregivers. "There were two variations on this theme: the first was concern that the child may not adapt to future placements other than the family home, and the second was concern about the adequacy of future services for the child" (Adams et al., 1990, p.54). Severe disabilities were operationalized in this study to include children who exhibit extreme deficits in language, motor, and cognitive skills and who require assistance to meet their fundamental needs (Adams et al., 1990).

With little other research addressing parental experiences over time in caring for a child or adult with autism, it is difficult to draw any firm conclusions. It may be that parents of children with autism experience more behavioural difficulties as their child ages. In addition, parents may experience concerns regarding the future of their child and what will happen to the child as parents age and are no longer able to act as primary caregivers. It is premature to draw conclusions until more research is conducted that focuses specifically on autism and its unique challenges and stressors over time.

In summary, it is clear that parents raising a child with autism have experiences that merit research focusing specifically on this disability. And while several authors have focused on behavioural and developmental concerns that face children with autism, there is little known about how parents experience this disability as a result of being faced with such challenges. For example, it is apparent from past research that parents raising a child with autism experience stress for a variety of reasons. However, we know little about how such stress is managed. In addition, autism has an onset and developmental course that is different from other childhood disabilities. Over time, mothers and fathers dealing with this disability are faced with issues related to the diagnosis and detection of autism. Furthermore, parents may struggle with the lack of independence of their children. An understanding of some of the above issues is necessary in order to better assist parents in managing when faced with this overwhelming challenge.

III. METHODOLOGY

With little information regarding the experiences of mothers and fathers over time in parenting a child with autism, it was important to choose an inductive method of inquiry. Researchers using an inductive approach to theory development do not organize data into a pre-chosen framework. Rather, theory in qualitative studies is developed from collected data. Grounded theory was chosen as the methodological approach to this research topic.

Grounded Theory

Grounded theory is one type of qualitative methodology. It is a highly systematic method of inquiry with the purpose of understanding social and psychological phenomenon and how individuals react in relation to such phenomena. Grounded theory makes the greatest contributions in areas where little research has been previously conducted (Chenitz & Swanson, 1986). Therefore, one of the major uses of this approach is in exploratory or descriptive studies.

In addition to being a method of inquiry useful for exploratory and descriptive research, grounded theory is process oriented and is useful in understanding phenomena and their relationships over time. The ultimate goal of analyzing qualitative data for process is to make sense of change in the phenomena begin studied over time. "Process serves to integrate the who, what, when, where, and why of the problem under study" (Fagerhaugh, 1986, p.144).

A main goal of grounded theory is to produce abstract concepts and make decisions regarding the relationships between these concepts (Chenitz & Swanson, 1986). In doing this, grounded theory uses the constant comparative method of analysis. Comparisons are made throughout the entire process of the research. Through the comparative process, conceptual categories are generated as a result of evidence found within the data. Conceptual categories are of a general nature, while the properties of the categories are more specific.

During data collection and analysis, the researcher identifies a core category which is a main theme around which all of the other categories revolve (Corbin, 1986). The core category is the "main concern or problem for the people in the setting" (Glaser, 1978, p. 94). Glaser (1978) describes a basic social process (BSP) as one type of core category which has "two or more emergent stages" and "gives the feeling of process, changes, and movement over time" (p. 97).

In addition to the core category, other general concepts related to the core category also are identified during the process of data collection and analysis. Grounded theory requires these identified concepts to be verified through continued data collection and analysis. This process continues until a concept or category becomes saturated. Saturation occurs when no additional data are being found that assist in redefining the properties of a conceptual category.

As continued comparison of cases takes place, the researcher develops hypotheses about the relationships between concepts. As hypotheses develop, they are also verified through further data collection and analysis. The end result is interrelated concepts that "form an integrated central theoretical framework - the core of the emerging theory" (Glaser & Strauss, 1967, p. 40).

Existing literature also plays a role in the process of theory development. The researcher examines existing literature in order to provide more data that may assist in the process of abstracting concepts. Ongoing review of existing literature also generates ideas about concepts and their relationships which may affect the direction of theorizing (Glaser, 1978).

There exists some debate in the literature regarding the relationship of reliability and validity to qualitative research. Reliability refers to the ability of other researchers to replicate a study. Since the use of the grounded theory method is dependent on the "researcher's skill, creativity, time, resources, and analytic ability" (Chenitz & Swanson, 1986, p. 13), it is difficult to replicate a grounded theory study exactly. Chenitz and Swanson (1986) have identified the application of the theory to similar situations and settings over time to be of more importance to reliability than whether or not the research can be replicated exactly.

A strategy that grounded theory researchers use to increase reliability, is to test hypotheses as they develop by checking with participants and their evaluation of the findings (Stern, 1985). This technique makes the findings reliable for the particular group that is being studied. Other techniques that could be used in qualitative research to increase reliability are peer evaluation and continued review of the literature (Field & Morse, 1985).

In qualitative research validity refers to the extent to which research results represent reality (Field & Morse, 1985). It focuses on the question of whether or not the theory is relevant to the group being studied. For example, a common threat to validity is the use of an inductive approach to a research question when a considerable amount is known about the topic.

Validity can be increased as a result of the researcher being aware of his/her own biases and assumptions and how those might affect the research process and the findings. As well, ongoing literature review during the data analysis and theory development process also helps to verify, elaborate, and identify factors which may not be evident in the hypotheses as they are being formulated (Chenitz & Swanson, 1986). Lastly, keeping detailed field notes throughout the research process also allows the researcher to identify potential threats to validity.

Grounded theory was chosen as the most appropriate method of inquiry for this study due to its usefulness in exploratory and descriptive research. There are few theories that focus specifically on the experience of raising a child with autism. Existing studies focusing on the experience of raising a child with a disability have included a number of disabilities as part of their samples. As well, researchers mainly have examined the experiences of mothers in relation to the experiencing of parenting a child with autism. We cannot assume that parents of children with varying disabilities will experience things in the same manner nor can we assume that both mothers and fathers will have the same experiences.

The experience of parenting a child with autism is one that takes place over the span of a lifetime. Little research has been conducted to examine the nature of this process as it relates to this disability. Autism is a unique disability with symptoms, onset, and developmental course that are very different from those of other developmental disabilities.

Due to the need to develop theory specific to parenting a child with autism and to better understand the experiences of parents of children with autism over time, grounded theory is an appropriate approach to this research. It will assist in developing a more specific and detailed understanding regarding the experience of parenting a child with autism as well as how both mothers and fathers may differ in their experience of this phenomenon.

Sampling and Data Collection

Sampling procedures in any research depend on the notion of representativeness. In many cases, "representativeness is assured by clarifying the critical variable(s) to be sought and assuring that there is a way to ascertain that the sample selected reflects these variables in the same way as does the population" (Kerlinger, 1973, p.9). In grounded theory research, the sample is not selected from the population based on certain variables prior to the study. "Rather, the initial sample is determined to examine the phenomena where it is found to exist" (Chenitz & Swanson, 1986, p.9). This sampling strategy is known as theoretical sampling. The use of theoretical sampling is a deliberate process based on the need to collect more data in order to examine the relationships between categories and to assure that representativeness exists in the data. Theoretical sampling has been described by Glaser (1978) as a method of sampling which depends on the process of data collection and analysis in order to promote the emergence of theory.

In using theoretical sampling, the researcher collects, codes, and analyzes the data and decides which data will be appropriate to collect next in order to develop emerging theory (Glaser, 1978). Such decisions regarding which data will be appropriate are based on the need for the researcher to collect data that will assist in theory development based on data that is being collected and coded during the interviewing process. Therefore, sampling is controlled by the emerging theory.

Participants

The means of data collection was formal, unstructured interviews. As a means of initiating the interviews, the researcher discussed with participants the purpose of the study and the rights of the informants as participants in the study. Consent forms were signed by all individuals willing to participate (Appendix A). Demographic data were collected in order to assist the researcher in identifying characteristics of the sample (Appendix B). Each participant was interviewed a minimum of two times, with the exception of two participants, both whom moved from Edmonton prior to the second interview being conducted. Each interview was approximately one hour in length.

As data collection and analysis took place, theoretical sampling dictated the need to interview parents with varying characteristics and differing experiences. For example, participants were chosen as members of the sample due to the stage of the process that they were in and/or the age of their child with autism, the birth order of the children in the family, and the gender of both the child with autism as well as the parents.

Parents who had a child with autism were identified as potential participants in this study. For practical reasons, parents were required to reside in Edmonton, Alberta or surrounding areas. They must have been willing to discuss their experiences in parenting a child with autism. The process of meeting with the first participant and subsequent participants included a meeting at either the informants' homes or the researcher's home. Initial contact was made with parents of children with autism at a Parent Support Group meeting hosted by the Edmonton Autism Society. An oral call for participants (Appendix C) was read to the parents at the support group meeting. Those individuals willing to allow the researcher to contact them regarding potential participation in the study were asked to provide their telephone numbers. It was made clear that in providing telephone numbers, individuals were not making a decision to participate in the study. Rather, they were allowing the researcher permission to contact them to discuss the possibility of participating in the research. In addition, all parents at the Support Group meeting were given a handout describing the research and were asked to contact the researcher should they be interested in knowing more about the study (Appendix C).

Recruitment also took place using a newsletter distributed by the Edmonton Autism Society in Edmonton, Alberta. A call for participants was included in the monthly newsletter (Appendix C). Those individuals willing to participate in the study were asked to contact the researcher for additional details. Upon contact with potential participants, the researcher explained the research project and asked the parents the age and gender of their child with autism in order to assist in theoretical sampling. At that time a potential list of participants was generated and used in theoretical sampling.

Once a list of potential participants was created through both the Support Group and the Edmonton Autism Society's newsletter, the process of theoretical sampling began. The first participant chosen was the mother of a six year-old boy with autism whose experience in the beginning phases of the process, including assessment and diagnosis was relatively recent. She was chosen as the first participant as her experience appeared typical and because it seemed appropriate to begin the study with an understanding of the beginning stages of the experience of autism.

The final sample consisted of eight parents of children with autism from six different families. All individuals were married although one participant had separated from her husband during the course of the study. All but one family was currently living in the same residence as their child with autism. This participant's child with autism had been launched from the home and had been living in an institution several years prior to the participant's involvement in the research. Another family was involved in a shared-care situation in which their child stayed with a host family half of the time in order to provide the family with an opportunity for respite.

Of the eight participants, six were female and two were male. All of the female participants reported that their employment status had been affected as a result of the demands of their child with autism. The ages of the participants ranged from approximately 32 years to 65 years of age.

The procedure for interviews included participants being asked by the researcher to describe their experience in parenting a child with autism by starting at the beginning of their experience and continuing up to the present day. Guiding questions used in the interviews included: a) Starting from the beginning and continuing up to the present day, can you tell me what raising a child with autism has been like for you?, b) What do you remember about the beginning of the process of dealing with your child's disability?, c) What has it been like for you as time has passed? These guiding questions were used to assist participants in describing their experiences to the researcher.

The second participant was chosen due to the age of his child with autism. He was the father of a 14 year-old boy and as a result, had more experiences from which to draw and provided the ability to examine more closely the aspect of time as well as any gender differences that may exist in dealing with a child of a different gender as well as differences that may result due to the gender of the parent. In addition, this child was the first child born to this family and allowed the opportunity to examine how birth order may have played a role in his experiences.

Following the completion of the initial interviews with the first two participants, hypotheses were raised as to the importance of the gender of the participants in experiencing autism. The first participant alluded to differences in her experience due to being the one that carried the child for 9 months. The second participant made mention of his reaction to his child having autism as being very different from that of his spouse. As a result of the questions that were raised, the next two participants chosen were the spouses of the first two participants.

Another question raised as a result of earlier interviews was whether the gender of the child played an important role in experiencing autism. This question was raised as a result of comments made by participants regarding being less or more concerned depending on the gender of their child with autism. Some participants indicated that they were less concerned about the seriousness of behavioural observations or missed milestones because they made assumptions that boys develop more slowly than girls. Therefore, the next participant was chosen to examine further the possibility that the gender of the child played a role in parents' experiences. The fifth participant was chosen because she was the mother of a female child with autism.

Although data were generated that assisted in understanding the earlier stages of living with autism, there still existed gaps in the understanding of this time period and the common experiences with which it was associated. The next two participants were chosen as they were well-situated to be able to provide additional, more recent data regarding the early phases of raising a child with autism.

Following the completion of the above interviews, it became evident that additional information was needed to better understand the post-diagnosis experience. Interviews previously conducted provided some information regarding what parents experienced following the diagnosis of their child. However, with the children being relatively young, it was difficult to understand fully the implications of living with a child with autism over time. As a result, the next participant was chosen to assist in understanding the later stages of the process. This participant was the mother of a daughter with autism who was in her forties and had since been launched from her family's home.

As part of the process of data analysis, a set of conceptual categories were developed as a result of having completed first interviews. Second interviews, therefore, were focused on verifying information about categories and concepts that had been developed in earlier data collection and analysis (Appendix D). Interviews were conducted until the categories were considered saturated. Saturation of a category referred to the presence of a sufficient amount of data within a category so that it was considered theoretically complete.

Field notes containing supportive, descriptive information regarding the interviews as well as the researcher's thoughts about relationships between the concepts were kept as a reference to be used during data analysis. The field notes also provided direction during subsequent data collection.

Several themes were explored in second interviews. An example of a theme further examined in second interviews was that of the importance of social support. A common theme for parents in this study was the isolation that they experienced as part of parenting their child with autism. As the child aged it seemed as though parents were more comfortable in gaining access to supports. Early memos indicated that over time some participants found it necessary and somewhat easier to access support than they had previously. What remained unclear was how participants arrived at a point where they felt comfortable reaching out and accepting assistance and what the meaning of accepting support was for parents. In addition, it was also not clear whether the experience of gaining access to social supports was a process that was similar for all participants. Second interview questions focused on individual differences in terms of whether or not supports were accessed as well as what types of supports that participants found helpful. In addition, participants were asked to describe their experiences with social support, how they got to a point where they found they were able to reach out to others, and what the meaning of support was for them.

Another theme explored in second interviews was that of the experience of loss. First interviews indicated parallels between the experience of raising a child with autism and the experience of losing a child as a result of death. The exact reasons for these parallels were not entirely clear. Second interviews explored further comments made by participants indicating that they had experienced a grief process as a result of learning that their child had autism.

Other areas explored in second interviews centred on: 1) the challenges that participants faced in illustrating their concerns regarding their child to health professionals and others, 2) expectations that parents had upon learning that their child had autism and some of the differences in coping as a result, 3) the frustrations that parents reported experiencing as a result of not having their concerns validated as well as having to make adjustments to their lives, 4) the difficulty that participants experienced following the diagnosis of their child, especially when they saw other people's children that appeared to be developing normally, 5) the ways that the diagnosis was presented to the family and the impact of that, and 6) the experience of attempting to normalize the experience of raising a child with autism (Appendix D).

Data Analysis

Interviews were tape recorded and transcribed. Transcription took place as soon as possible after the termination of each interview. The constant comparative method of data analysis was performed (Glaser & Strauss, 1967). Following transcription, the researcher began by reading over the interview scripts and began making memos beside statements made by the participants. Memos were made in relation to emerging ideas that described the experience of parenting a child with autism. This began the process of coding the transcripts line by line. When an idea or experience emerged across successive interviews, a category was developed to encompass the theme related to those ideas or experiences.

Once first interviews were completed, there were certain commonalities that were identified as part of the experiences of participants. They experienced some common issues as part of caring for their children. These common experiences developed into major categories of the theory. To facilitate the process of further category development, memos were generated to question the differences between participants' experiences and to assist in identifying areas of commonality.

Many participants in first interviews made references to the word normal when discussing their children's early stages of development. Questions were raised by the researcher through the analysis of data regarding whether there exists a period of normal development or whether indications of autism are present very early in the child's development.

Initially, it appeared that parents did experience a period of normalcy following the birth of their child. They spoke of being happy and feeling as though the time following the birth of their child was a magical time that went along perfectly. With further data collection, however, it became less clear what the commonalities were between parents in the early stages of the process. Some participants expressed a belief in the fact that their child had characteristics of autism from birth and did not develop normally as they had expected. With further questioning around this topic it became clear that even those that had indicated feeling that their child had autism from birth, did experience a period of expecting their child to be developing normally. It appeared as though the assumption that parents had that their children had autism very early on was as a result of knowledge that they had developed due to examining their situation retrospectively.

Initial interview memos also raised questions regarding whether other individuals or family members were involved in the experience of dealing with autism, especially in the earlier phases which included concerns regarding the possibility that something was wrong with their child. Although some participants mentioned that others were involved, others failed to mention the involvement of anyone else. What was unclear was whether anyone was involved in assisting parents during the period of time during which they began to increase their concern regarding the possibility that something was seriously wrong with their child. Some participants appeared to indicate that this is an internal process while others clearly relied on outside sources to validate their concerns. The differences that were noticed in terms of how parents experienced autism raised the possibility that individuals experienced things differently as a result of having different styles of coping. Further questions around the involvement of others in the process were asked in order to clarify this issue.

The above are examples of memos and early questions that were raised and derived from the first interviews with participants. Following the development of memos related to the commonalities that existed within the data, data analysis next included grouping statements or ideas according to similarities.

Each similar group was given a category name. Examples of earlier categories included: Assuming Normalcy, Emerging Recognition, Seeking Information, Searching for Evidence of Normalcy, Coming to Terms with Autism, Learning to Live with Autism, and Restarting Life. As data analysis continued, categories changed and were combined in order to more accurately reflect the data and the experiences of participants.

Categories changed and developed and data collection and analysis proceeded. For example, the stage initially titled Emerging Recognition changed to Worrying about Differences to more accurately describe the main theme of this stage. The main theme of this time in parents' lives was the worry that they experienced as a result of certain behaviours that they were observing in their children. Another example of a change in a category was the stage initially entitled Learning to Live with Autism. As data collection and analysis took place, this stage changed. At one point it was thought that the main theme of the stage was the process of learning to live with autism that took place for parents. While learning to live with autism is a sub-theme of this stage, with further analysis, it seemed as though a process of redefining expectations more accurately described the main process that parents experienced. Finally, it was decided that Taking Action more adequately incorporated both aspects of learning to live with autism as well as the process of redefining expectations that took place for parents.

IV. FINDINGS

An assumption of the grounded theory method of inquiry is "that all groups share a specific social psychological 'problem'" (Hutchinson, 1986, p. 196). The basic social psychological problem in this study was reframing the vision of the child and family. Throughout the process, parents integrated their expectations of what they had hoped their life would be like with the reality of the demands of their life with a child with autism.

All other categories were incorporated into the core category. As data were collected and analyzed, six stages of the experience of raising a child with autism were identified and became the subcategories of the core category.

Stage I: Expecting Normal

The first stage in the process of raising a child with autism begins upon the birth of the child. Foundations for this stage are formed prior to pregnancy. The main theme of this stage is the expectations that participants developed regarding their child's development. Participants had notions of the experience of parenting and normative child development. Following the birth of their child, they expected that their child would develop according to those notions. Throughout this stage the term normal was used to refer to the child meeting appropriate developmental milestones. During this stage parents reported differing reactions as a result of having begun checking their expectations regarding their child's development. Some found that upon comparing their child with their views and with other children, they were convinced that their child was developing normally. Others reported noticing aspects of development that did not fit with their vision.

Participants reported using two means of checking the expectations that they had established regarding the development of their child. The first was by examining against their vision and expectations regarding what their child would be like. A mother discussed the view that she had developed regarding her child prior to her child's birth:

> ... I think certainly obviously we were looking toward just having a healthy child. ... But it didn't occur to me that ... problems could ensue later on or that you could find out that when your child is two or three years old that there could be something developmentally wrong with them (5f2).

Participants reported that their vision for their child was one of expecting normal development. They indicated having expectations that their child would meet developmental milestones, including developing language, learning to walk, learning social skills, as well as other expectations regarding what normal development would look like. Due to having these expectations a mother articulated her experience of relief following the birth of her child:

> ... it was just a relief to have her be born and count all of her fingers and toes and say they're there and oh yes, we have a wonderfully normal child.

> And she seemed alert and responsive ... Because I think in our mind that when there's something wrong with your child it's going to be obvious from the get-go. That's it's gonna be something that they kind of rubber stamp them in the hospital and they go off to their families and this one's good and this one's bad ... (5f2).

Other parents commented regarding the expectations that they had for their children following birth. In discussing her experiences around expecting normal, a mother stated:

> ... you look to the immediate future, you know, ... growing up, teen years. ... I think you hope they'll be happy or something like that, or successful. I think we all wish this for our children (8f2).

A second way that parents checked their expectations of normal development was by comparing their child against what they saw as normal development in other children. Participants evaluated their expectations by comparing their child to other children in the family or to children at similar developmental levels. A mother spoke of her experience and the importance of comparing her second child with her first:

> ... because [he] was my second child and I was so close to the first one and so interested in my first child's development, I had that experience that helped me... It's a kind of framework (6f2).

Others with other children in their families with which to compare indicated checking specific aspects of their children's development. A father stated of his experience:

> [What I was looking for was] ... that he was able to do the things that his sister could do at times. Like rolling over, walking, basic language, all came to him about the same time (3m2).

Other parents reported checking their expectations of normal against children in other contexts. Often this involved checking development through social situations, including play groups or other social contexts. A mother talked of her experience with a play group as being important to the comparison process:

> I think ... the biggest thing was what I was talking about at the play group. Seeing normal children at that normal stage of development and that for me was, for me to go to that playgroup three times a week I could see what normal children were doing at that age (5f1).

Another parent spoke of comparing her son with other children in her neighborhood:

> ... I remember when he was ... maybe 8 or 9 months I became friends with a parent in our neighborhood. And she had a baby who was about a month older than ... [our son]. And I remember seeing that there was a lot of differences between the two of them with her son being a lot happier and more easygoing and a lot more responsive than my son (4f1).

Regardless of the means used to check the vision of normal development, the expectation was that the children would develop in a similar fashion to other children of the same age. Upon comparing, most parents indicated that their children's development was fitting with their vision. A mother spoke of feeling that her child was developing cognitively according to her expectations:

> ... [she] seemed extremely bright. ... She had a fantastic memory. Somebody would come in with a red tie, she would remember a month later (8f2).

Other parents made observations about the ways in which their child responded to the environment and the temperament with which they interacted. A father indicated about his son:

> [he]... was reacting to parents the way that any other child would. [He was] reacting to his name when called. ... Eating, just everything was normal (3m2).

Regarding her son's temperament and appearance a mother stated:

> ... he was a perfect, perfect, baby. He was so cute, he was a happy baby, ... and so everything just went along magically ... (1f1).

A mother discussed a routine medical appointment at which time she was told that her child was developing normally:

> From 4 months old when I went to the health unit. When the nurse told me, "He's completely normal, he's cute, he responds so well to every test..." And she said, "Congratulations, everything is fine" (6f1).

While most participants indicated feeling that their children were developing according to their vision, others noticed small differences. Some parents noticed aspects of development that did not fit with their views of normal development. However, such differences were dismissed and parents did not find reason to be concerned. A mother discussed her experience in this regard, almost immediately following the birth of her daughter:

> ... from day one, from the hospital I thought, "This seems strange." ... She cried a lot. ... She didn't like to be held, it seemed like she was kind of repulsed by human contact. And that seemed very strange to me. She would arch her back and try to almost get away, even as a little baby, as an

> infant. ... Even a couple of days, a couple of weeks home from the hospital. And ... I remember thinking that and then sort of dismissing it thinking, "That's ridiculous. How could that be possible?" (5f2).

Of her experience another mother stated that she had thought her son had colic as a result of the behaviours he was exhibiting:

> ... when my first child, when he cried ... it was for a certain period of time, but I could calm him down, help him, to comfort him. By feeding him if he was cold or too warm. I could help. But with [my second son] he was two weeks old and there was no way. And I was wondering if it was colic because my first child had colic for many months (6f2).

Stage II: Worrying about Differences

The second stage identified by participants as part of the process of raising their child is Worrying about Differences. During this stage participants began to notice discrepancies between the expectations that they had regarding their children as well as the differences between their children's development and that of other children. Although some parents had noticed differences in the previous stages, they found that during this stage they were unable to dismiss what they noticed. The first aspect of development that caused parents to worry during this stage was that of missed milestones. Other aspects of development that they noticed were odd behaviours. Such behaviours were very odd and could not be ignored by parents.

Some participants indicated that they began to notice a lack of normal development in their children. They began to recognize that their child was not meeting fundamental developmental milestones, which included not developing language, losing previously developed language, as well as other communication or social difficulties. These behaviours caused parents to become concerned. A mother described her son's lack of language development: "And then in the summer we started to notice that he wasn't talking" (1f1).

Another parent indicated that his son had lost certain language capacities that were previously developing well:

> And then things just started falling apart. You know, he lost words and would stop talking and ... would stop saying the words that he had. Which we thought, well maybe he's just lost that word, he's just not saying it. ....We thought he was having hearing problems and the big kicker was that he would never respond to us anymore verbally and he had always done that right from the get-go (3m1, 3m2).

A mother affirmed this father's experience by speaking of her son's loss of words:

> We think of it as he just sort of gradually sort of started shutting down more and more and more. So the words he had, the language that he had, all of a sudden he wouldn't say. And that, from the little boy that... would run to the door to greet you and would be so involved in the party. ...Next thing we knew is that he was ... just totally isolated from... the rest of us. That he just didn't respond (1f2).

Other parents concurred with concerns regarding missed milestones and lack of development. Aside from language, children during this stage were missing other milestones, including those related to social development and other aspects of communication. A mother discussed her son's difficulties both in terms of language development as well as communication:

> … when [our son] was about 18 months we started noticing not so much that he was doing strange things but it was the lack of things that he was doing. … Not pointing, not trying to make any attempts to speak (7f1).

Another mother concurred with observations of communication difficulties:

> There was no eye contact, there was no way to communicate. … He communicated with me only when he could. But there was no consistency (6f2).

Also during this stage, participants began to notice odd behaviours that did not seem to fit with their views or experiences regarding the way that their child should be developing. Such behaviours included fixation on certain stimuli, lack of eye contact, arm-flapping, breathing difficulties, and echolalia. A mother described her son's lack of interaction:

> … I remember very well when he was about from 8 months old he was sitting in the living room and watching his hands for hours. And I wanted to interact with him and he didn't seem to respond and I was very worried (6f1).

Another participant also indicated noticing a certain strangeness in terms of her son's pattern of interacting:

> … right after the surgery … he was sitting on the resident doctor's lap and he was looking at me …, but it looked like he was looking through me (4f1).

Aside from strange social interaction patterns, participants noticed oddities in other areas. A parent described the behaviours that he and his wife had not seen previously:

> And then I remember in the summer, probably July or August, he started flapping his arms and ... we didn't know what it was, just whatever (3m2).

Other behaviours identified as odd included excessive crying, which in one case caused a mother serious alarm:

> ... the way that he cried was unusual to the point that he couldn't breathe normally, he'd turn blue and stop breathing for too long. And it was without stop (6f2).

Lastly, a mother recognized that her daughter was repeating phrases that she and other family members would say:

> ... she started doing things like ... when you asked her something, echolalia. You know, she would repeat it. ... She would repeat things like, "Do you want a cookie? Do you want a cookie?" (8f1, 8f2).

Participants during this stage did not know how to explain the behaviours and/or lack of development that they were noticing. Most indicated that they felt reason to be concerned and sought assurance from friends and family members about what they were seeing by putting their concerns into words for the first time. A mother indicated checking with parents from her daughter's playgroup regarding her concerns:

> And I remember asking the other moms in the playgroup if they noticed anything different or strange about her (5f1).

Another parent spoke of verbalizing her concerns to her neighbour:

> So you'd say to the lady next door or down the hall about [our daughter] doing this [echolalia], and they'd say, "Oh yes, my son did that and it's a

> habit they get into. They're learning speech so they repeat what you've said" (8f1).

Parents indicated that in verbalizing to others their worries, they were hoping for assurance and support that their child was developing appropriately. Usually parents were given the assurance for which they wished. A mother spoke of her husband's reaction to her worry:

> My husband told me, "Stop saying that kind of thing. It's not possible [that something is wrong]. He's just different from the first one" (6f1).

Others shared in the experience of having immediate family members tell them that everything was okay. A participant spoke of her husband's reaction to her concerns:

> ...he, [my husband], was really unprepared to hear any of that from me. ... It was his defense to really go the other way and really try to convince me ... that everything was right about her (5f1).

A participant described addressing her concerns with her in-laws:

> ... by the time he was a year my in-laws ... came over to visit and I asked them if there was anything unusual about him. They were really child-oriented and loved babies and all that. And my mother-in-law said, "No, there's nothing wrong with him" (4f1).

While it appeared to be most common for participants to share what they were noticing with individuals inside the immediate family, others spoke of articulating their concerns to friends. Reactions from those outside the family tended to be similar. In discussing with other parents what she had noticed in terms of her son's language development a mother got the following reaction:

> … people would say, “Oh, there’s nothing wrong with him, Einstein didn’t talk until he was four” (4f1).

Another mother received validation from parents of children that were involved in a play group:

> And I remember asking the other moms in the playgroup if they noticed anything different or strange about her. And they said, “Oh no, she sort of … likes to keep to herself and everything but, you know, she’ll grow out of this” (5f1).

Stage III: Needing to Know

The next stage focused on parents needing to know what was happening with their child. Throughout the previous stage, parents were given assurance that they did not have reason to be worried. Many did not accept the assurance that they received and felt that they needed more information to explain what they were noticing. Participants during this stage began the process of acquiring information due to an awareness that there may be something not quite right with their child’s development. Parents made a decision to further explore their concerns by accessing formal avenues of information. A second aspect of this stage is that many parents, although now wanting information and support, did not receive the information that they wanted.

Parents by this time reported feeling very worried about their child’s development. In many cases, new symptoms began to develop. As well, symptoms and behaviours noticed in the previous stage worsened. A mother described the continuation and worsening of the odd behaviours of her son:

> He ... was impulsive also, he played with soil everywhere. ... And I couldn't leave him one second. Because it was a mess everywhere in the house. He jumped off the table and was nude. He took off his ... diaper and jumps every, everywhere. He spit without stop. ... He couldn't sit, he couldn't (6f1).

Of the behaviours that her daughter was exhibiting to cause more serious concern a mother stated:

> And she wasn't interested in being around the other kids at all. And her language still was very strange and not social and the other kids were referring to their mom as mommy and I thought, "She doesn't do that." You know, that's really strange (5f1).

With their level of concern increasing, parents found it necessary to look for resources and supports that would assist in explaining what they were observing might mean. The resources that parents sought included the opinions of professionals within the community as well as other sources, including literature. A mother spoke of needing to know how to explain her daughter's behaviours:

> ... I just picked up [my husband's] pediatrics textbook which didn't have a lot in it, but it had a little chapter on Pervasive Developmental Disorder and I looked through it and was horrified because I knew that it was her. And there was a little vignette about a boy that sounded almost completely, exactly like her and I was horrified at the thought of it and I knew in my heart at the time that that's what the problem was (5f2).

Other parents have indicated that they sought information within the formal health care system. Parents discussed the need at this time to consult with pediatricians or general practitioners regarding their child's development. Concerns brought to the attention of health care professionals tended to focus on such issues as hearing, lack of responsiveness, lack of language development, and lack of affection. A mother spoke of her worriedness regarding her son in terms of both his language and social responsiveness:

> I'm worried, very worried about his development. No speech, but no babbling, no cuddling, nothing (6f1).

Other parents conveyed worriedness regarding communication difficulties as their children did not appear to respond appropriately to them. A mother talked of her experience in trying to relate to her daughter:

> ...I wondered if she was a bit deaf. You know, I would talk to her and she would not reply on occasion (8f1).

Of similar concerns that she presented to the doctor a mother stated:

> ... it was like we were talking in Greek. He had no concept of conversations and so, "Point to your nose." He never, you know, two months of [my husband] playing the point to your nose game and he still isn't pointing to his nose. Or [telling him to go] get his coat. You know, things that even if children couldn't express themselves, they could respond to language. And that for me was before I knew about expressive and receptive language. And that was the one thing that really stood out, was that receptively, he hasn't got a clue (1f2).

Parents often did not get the information for which they were looking. Contact with the health care system tended to vary and the success of participants in acquiring the information that they wanted depended on two factors. Such factors included the doctors' level of expertise regarding developmental difficulties and the persistence of parents in seeking the information. Parents indicated feeling frustrated with their experiences.

One aspect of the frustration was related to the difficulty parents had in articulating their concerns. A mother described her experience in explaining to health care professionals what she had noticed:

> And I knew there was something unusual but it was very hard for me to explain what it was and it was very frustrating to know that at the hospital nothing happened (6f1).

In addition to the frustration of attempting to explain their children's difficulties and behaviours to others, parents spoke of feeling frustrated with the reactions that they received from physicians and other professionals. Participants reported that after expressing their concerns to others they were initially dismissed. There were three ways in which doctors dismissed parents' concerns: 1) by assuring them that there was not a problem with their child. A mother stated:

> I went to the U of A Hospital. And she said, "I don't see [anything wrong]." It was just the opposite. "He's typical, he's normal. He has a delay of speech probably because he had a lot of ear infections but I don't see anything" (6f1).

2) by reserving judgement. Oftentimes doctors told parents that although they noticed difficulties, they should not be concerned or should reserve judgement

until their child was older. A participant described her concerns being dismissed due to the young age of her child and the short time that the physician spent examining him:

> I said, "I'm very worried. At 8 months old this child doesn't respond at all the way most of them do, ... I'm very worried." And he said, "Now he's young. We're gonna help you to observe the development." ... He couldn't validate what I observed because he saw him for ten minutes (6f2).

Other parents related to having their concerns dismissed as a result of the age of their child. Oftentimes, physicians would state that it was too early to be worried. A mother described such an experience:

> And the doctor said, "Oh, we don't have to be worried now. He's just 12 months old. And that's fine he doesn't speak" (6f1).

Of her several visits to the doctor, a parent spoke of receiving confirmation that her child was developing normally and that if she continued to have worries, they should be addressed once the child was somewhat older:

> ... we went to the pediatrician quite a few times. ... He was saying, "Don't worry about it. You know, wait until he's at least three." You know, right from about eighteen months on he was saying, "Wait until he's over two." And then when he was two, it was, "Wait until he's over three. Everything's fine. He's developing normally." ... It was very, very frustrating. Nights and nights of crying and crying and just why didn't anybody listen to us? (7f1).

Another parent spoke of a similar experience in relating her concerns to the doctor:

> Well I just sort of articulated what I saw and I was not dismissed in the sense of, "Oh, this is silly." I remember what was said at the time was, "I kind of hear your concerns, but she's also kind of young." And you get this speech about the spread in development for kids, right? And I remember thinking, "It's more than that." It's not just the fact that some of this stuff is ... how to say it? It's not even that she was starting to show even the glimpses of some of the beginning of some of those skills, it's just that they weren't there and they showed no signs of coming. And I guess that's sort of what I tried to convey to this pediatrician (5f2).

3) by blaming the parents for the behaviours that had surfaced in their child. A mother spoke of her experience of being blamed for her son's difficulties:

> And my professors told me, "Don't be too worried, every child is different. Be careful for the future if you are overprotective like that with your children you can cause more problems than you think. Cause maybe you have yourself a lot of problems" (6f1).

Other parents have had similar experiences that have caused them to feel at fault for some of the behaviours that their children were exhibiting. A father spoke of his wife's experience with a pediatrician that he felt was damaging at the time:

> There was one awful situation that ... [my wife] was in where, unfortunately I wasn't there. ... The pediatrician just started reading the riot act to [my wife] about being an overly indulgent parent and [said]..., "If you keep treating him like this he'll be stealing cars by the time he's fourteen" (2m1).

Participants have indicated that it was a frustrating experience to be dismissed by professionals when they approached them with concerns. The lack of support that parents received caused them to doubt their own judgement and question their parenting capabilities. A mother spoke of her experience of questioning her skills:

> I felt so bad because everybody denied that there was something wrong. ... But... I felt guilty in a way, not to know how to deal with that kind of child. And I felt so guilty I thought it's cause my child, from that time, when the speech pathologist told me, "Maybe it's you, you have a problem. You need to stop comparing your child with the first one and maybe to rest." Because I was a full-time student at university and a full-time mom at home. And but at that time I knew there was something wrong. I knew. But the problem was I took every problem I saw in my child towards me. I felt guilty. I thought it was, everything was cause of me because nobody validated what I really noticed (6f1).

In speaking of her experience, another mother discussed how the comments made to her by her doctor caused her to doubt her judgement:

> It was a horrible, horrible experience. And, ... he was implying that [my son] was manipulating me and I was spending every ounce of my energy trying to console him. So I ended up looking at [my son] and saying, "Is this what you're doing to me, are you manipulating me?" You know, I was just humiliated (3f1).

Stage IV: Having it Real

During this stage, parents reported having felt heard by the health care system for the first time. Due to the persistence of parents in needing to know what was wrong with their child, they received a referral for a specialized assessment during this stage. For the first time the word autism was mentioned. By the end of this stage, parents had learned from professionals that their child was officially diagnosed with autism. Parents then attempted to make sense of autism and the reality of their new world.

At the beginning of this stage parents indicated the importance of persisting by making frequent visits to the doctor in order to acquire the support that they needed. Of her frequent visits to the doctor a mother stated:

> … We started going to the pediatrician pretty much monthly because things weren't improving, and pushing and pushing. And finally after a year and half of that, from the time he was eighteen months to the time he was three. It took that long to get him assessed (7f1).

Another parent voiced the need to be persistent:

> When I talked to the speech pathologist, I said, "…And nothing works, I feel useless. I feel powerless. I don't know what to do." It was on the phone. And I said, "I need some help, please. It's an emergency" (6f2).

As a result of parental persistence in many cases, participants were referred for an assessment to determine the nature of their children's developmental delays. This meant being referred to another, more specialized, level of the health care system. The assessment process was one that took place over the course of one or two days. Parents reported feeling anxiety about the process of receiving the assessment for their child. Although they did not know what to expect, they reported feeling anxious due to the perceived seriousness of the situation and the need for an assessment to take place. As well, there was anxiety around the fact that parents would now learn the specifics regarding their children's developmental capacities. A mother described her anxiety with respect to having her son assessed:

> And the actual assessment itself ... I was an absolute nutcase about it by the time it came. I was just on pins and needles, a really hard day for [our son] to get through (4f1).

Other parents agreed with the assessment process being difficult. A mother spoke of her experience in this regard:

> And ... we arrived at the Glenrose and went through the whole rigors of that and... it was a difficult experience, more difficult than I anticipated (1f1).

In describing the assessment another parent spoke of the difficulty that she had in learning the exact nature of her daughter's delays:

> Well that assessment process as you know is a couple of days in length and it was probably a little more difficult than I thought it would have been. ... But during that experience of two days I think what was hard about it was to find out the finer details about ... where her difficulties were and ... where you plot your child in terms of their development (5f2).

Following the assessment process, parents learned that their children had autism. Parents spoke of the shock that they experienced as a result of having heard the diagnosis for certain. A parent expressed the difficulty that she had in this regard:

> ... I wasn't prepared for the fact of hearing it. I think, having it real. And I remember thinking that it is almost one of those things you can't turn back after that. ... I remember almost feeling like I was out of my body when I was hearing it (5f1).

Others related the difficulty of having the diagnosis confirmed. Of the shock that she experienced a mother stated:

> ...it was the biggest shock of my life. I felt like the whole world had just opened up and just engulfed me. There was nothing that had prepared me (1f1).

The spouse of the above participant agreed with the experience of shock:

> ... we heard the word from the pediatrician. ... She said she saw signs of autism and that just blew us out of the water (3m2).

In this stage, the learning of the diagnosis confirmed many parents' suspicions. Despite the unpreparedness of hearing the diagnosis, participants also spoke of feeling a sense of relief at having autism made real. In previous stages, parents searched for information and recognition regarding behaviours and developmental delays that they noticed and did not receive any. Many parents doubted their own judgement or experienced guilt as a result of not being provided with the necessary information to explain their concerns. They reported finally having the recognition that they searched for in the previous stage. A mother spoke of being able to let go of her feelings of self-blame:

> It was a relief cause I always asked for help and people always blamed me. ... It was a real relief cause, from that time I didn't feel guilty at all. It's extremely frustrating to give and give and give and give without stop and not get results (6f1).

Another parent agreed with the diagnosis providing the opportunity to release feelings of self-blame:

> But then I'd have to say that having that diagnosis was terrible in a sense but in a way it was kind of a relief and it was, it was almost like a burden was lifted off of me because then I realized that this is not our fault. And this is not something that we have inflicted upon her (5f1).

In addition to the sense of relief in knowing that what they had noticed previously was legitimate, parents expressed feeling relief that they finally had an explanation for their son or daughter's behaviours. Of her experience of relief in this regard a mother stated:

> It was a relief. It was a relief to finally know what it was. Because once I knew what it was I could find books and understand, learn to understand how to deal with him and how to help him learn (7f1).

Although all parents reported experiencing a sense of shock and relief, there were variations in the speed at which parents were able to integrate the diagnosis after hearing it for the first time. Some participants did not fully understand the reality of the situation while others immediately were devastated. For example, some participants indicated that they had convinced themselves and sometimes others, that the prognosis for their child was not so bad. A mother stated about wanting to believe that her child's diagnosis was mild:

> I think I was holding out the hope that [she would be mild]... cause somehow in my mind [I was] thinking that it would be easier to deal with somehow if she was mild.

In elaborating on her hope for her daughter's diagnosis to be mild, the same parent expressed her views regarding treatment as a result:

> I think that both [my husband] and I were holding out for the fact that yes, she may be autistic but it is probably mild. ... And I think secretly in the back of our minds we thought that some way we could find some treatment that would normalize her (5f1).

Other participants agreed with the hope that their children's autism would be mild. A mother spoke of her experience in describing her son's disability to others:

> So that's when I knew it was autism and not autistic tendencies. ... I even went around telling people that he had mild autism. We thought he was quite bright at that point. He was able to put together puzzles with great speed ... and the way he slapped together a puzzle was quite phenomenal (4f1).

The hope that the diagnosis would be mild tended to be the result of a number of factors including previous knowledge and experience regarding autism, the ways in which the child behaved, and the manner in which the diagnosis was presented to families.

Those that had little prior knowledge and experience with autism reported not knowing what to expect upon learning the diagnosis. Since they had no frame of reference, parents reported expecting their child's prognosis to be less severe than they later learned it was. A father speaks of his experience and the hope that he had that his son's disability would be mild:

> I didn't know what to expect from it. I remember he did lots of things normally, physically. So I always kind of held out the hope that he really wasn't severe because he had good gross motor skills. ... I was trying to hope, ... lean on the stuff that he could do. And hope it wasn't as bad... (3m2).

A mother concurred with the impact that lack of knowledge regarding autism had on her interpretation of the disability:

> ... and I didn't have a very realistic understanding of what autism was. I mean, what I saw was, you know, this child totally withdrawn with no affection and hiding and hitting themselves in the corner. I mean, that was my image of autism and [our son] had always been extremely affectionate with me, so that was of course my first response. I thought, it can't be because he's so affectionate (1f1).

Still other parents reported that their belief that their child's diagnosis would be mild was largely due to the fact that he/she was showing some signs of development which were age-appropriate. A mother stated of her son's ability to communicate:

> But the doctor told my husband and I, "You worked a lot with that child. It is obvious. Cause he can have eye contact which is not perfect, but he tries to communicate" (6f1).

A father described his son's language development as contributing to his belief that he must be okay:

> ... he's doing some extraordinary things, he's learning the alphabet. ... So he must be okay, right? (2m1).

Lastly, parents spoke about the way in which the diagnosis was presented as being a factor in their interpretation of the situation. A father spoke of the way that the diagnosis was presented to his family:

> ... when he was diagnosed I don't think I understood the significance of the affliction. ... The diagnosis was done by somebody at the Glenrose who was very upbeat about [our son's] potential. And, ... I think in retrospect, unreasonably upbeat (2m1).

The above parent indicated that the optimism with which the diagnosis was presented caused him to view his son's prognosis in an unrealistic light. Another parent agreed:

> ... the doctor told us, "You know there are several programs that exist and your child has a lot of delays in his development. But about creativity we don't see problems, about cognitive development. It was uneven, but we are sure he can go to school. ... We can see that he's bright" (6f2).

While the majority of participants indicated that their reaction to learning the diagnosis of their child was one of expecting the prognosis to be good, others stated that the reality of the situation affected them immediately and they expected the worst for their child's future. A mother spoke of her experience of expecting the worst immediately following the diagnosis of her son:

> It was a life sentence. It was, it was the most horrific thing I could imagine. ... [My husband's] mom was the, she was the expeditor. She just pulled in all the stops. ... I needed someone to mobilize me cause I was so depressed. ... So I admire some parents that get right on it a lot faster than what I was able to do (1f2).

Another mother that had previously hoped that her child would have mild autism, stated that upon learning the details of her daughter's functioning level, she was devastated:

> You know, she's at a 9 month level here or an 18 month level there. That was devastating for me. As a matter of fact, it really took me off guard. ... And I remember hanging on to the chair thinking I was going to fall off it because I was unprepared. I knew she was lagging behind in her development, I thought, "Maybe a year in this." I just had no idea and it really, really threw me for a loop as to find out exactly, you know, the seriousness, I guess. I guess we were holding out for the fact that, "Yes,

> she's autistic, but it's mild." You know, that's kind of what I wanted to hear. And to leave that process and find out that she was not only autistic, but she was quite severe, in the severe-profound category, that just about killed me (5f2).

Once participants were able to integrate the reality of the diagnosis all reported feeling a profound sense of loss. They attributed the feeling of loss to having to let go of and modify the expectations regarding their child that they had previously developed. Many parents have likened this sense of loss as a result of their expectations not being met to that experienced by a parent when a child is lost through death. Part of the profound sense of loss that parents experienced appeared to be a result of having to let go of the expectations that they developed for the child that they brought home from the hospital. In relating his sense of loss a father stated:

> It is like a death. Cause I mean in, like I said, [my son] died for me in, you know, May and June of 1994. He's not the kid who we brought home from the hospital. He's just a completely different being, it seems (3m1).

Others agreed with having to let go of expectations that they had for their child. A mother stated of her experience:

> You know, I think in some ways for us ... it was like [our son] died. Really like dealing with his death and we got in his place ... something far ... [different] than the earlier edition (1f1).

Another mother spoke of experiencing loss as a result of having to let go of the expectations that she had for her daughter's future:

> It's terrible, you know, it's like a death. You know, it's just like somebody took your heart and ripped it out. And I remember thinking that night just how awful I felt because ... I felt terrible for her that she would ... never have any of these opportunities that we all hoped for her or wanted for her. That she would miss out on all of that (5f1).

A parent reported the difficulty that she experienced in not having the emotional space to deal with her grief as a result of the demands of her child:

> ... it's probably in my opinion worse than when a parent actually loses a child because they have died. Because ... for the first little while ... you are grieving the child that you thought you had and this other child that you really don't know and understand but you have to be there for and take care of twenty-four hours a day (7f1).

As a result of the sense of loss and the challenges in accepting the reality of their situation, participants during this stage reported finding it difficult to be in social situations. The challenges of understanding the implications of a lifelong disability caused parents to avoid obtaining both formal and informal supports for their family at this time. The first reason for this was that parents reported having difficulties discussing their circumstances, especially since the diagnosis was new. Of her experience a mother stated:

> ... so it was really painful to be around our friends and ... we felt really isolated for a fairly long stretch. And some of that was self-imposed because we couldn't talk about it (1f1).

A second reason for the isolation that parents experienced was that they felt that others did not understand their situation. Of this belief a mother stated:

> ... anybody that you talk to, even friends that are close to you, don't get it. They just don't understand what you are going through (7f1).

Another parent agreed with the lack of understanding of others:

> It was a mix of emotions but I was extremely sad for a long time. Sad and so apart from other people. Cause I felt isolated and as if nobody could understand and nobody could help (6f1).

The last reason that parents isolated themselves from others was because they found it painful to be around other children at similar ages to their children with autism. Seeing other children who appeared to be developing normally contributed greatly to parents' sense of loss. In seeing what other children were able to do, it was made obvious to parents what their child was unable to do. When asked what she found difficult about seeing other children a mother responded:

> ... because my child still looked normal. The problem is in the brain. I cannot put a label on his forehead and say, "He is different, respect the difference." ... And I saw these children and parents who were proud and happy and I told myself, "I would just like everybody to appreciate that there's a connection with the balance in their child's brain and the body." And mine, there's something very, very difficult, very wrong. It's a big problem in the brain. I was ... upset. I was upset (6f2).

Of having a similar experience another parent stated:

> I actually found it very painful [to be around other children] who were [my daughter's age]. And my niece who was a year older ..., I just found, I found myself not wanting to be at family functions and not wanting to be around her. And I mean, she's a sweet little girl who is oblivious to all of it. But I remember thinking, "It kills me to see other kids who [are] doing what my child [should be] doing." And I remember thinking just how unjust it was and how, you know, you think you do all the right things during your pregnancy or whatever to be able to produce this normal, perfect child and I remember just thinking ..., "It's not fair." And I

> remember looking at other kids in the grocery store and … thinking, "Gosh, don't you realize what you have?" … [I would] just … be really hypersensitive to that (5f2).

Stage V: Taking Action

During this stage parents began the process of taking action to be able to better understand and manage autism. Many participants indicated not having accurate information to be able to fully understand what they would be dealing with. Their knowledge and experience with autism was limited. Therefore, the decision to take action involved accessing the necessary supports in order to be able to adequately manage. As a result of having accessed support, participants then began to incorporate the knowledge that they had obtained. Part of the incorporation of information regarding autism involved a choice by parents to redefine the expectations that they had for themselves, their child with autism, and their family unit.

Participants had little previous knowledge of autism. Many stated that part of the challenge of learning to live with autism was a lack of understanding of the disability and the many ways it would impact upon their lives. For example, a father indicated that his only knowledge of autism was a result of having heard about it through the media:

> [I] … didn't know what it was basically. You know, you've heard of it, you know it's some kind of thing that causes whatever it causes and … the only reference I had was Dustin Hoffman and Rain Man … (3m2).

A mother spoke of the devastation she felt as a result of the lack of knowledge that she had regarding autism:

> … I felt so devastated in front of that kind of disability. I didn't know anybody who had a child with autism. I didn't know a lot about autism (6f2).

Another parent spoke of the limited understanding she had of autism:

> I had some very … I guess, sort of stereotypical notions about what it was. … I knew that stereotypical behaviour was part of it. But generally what I thought of was the kid rocking in the corner, you know, that that's what they do (5f1).

The lack of knowledge fueled parents' decisions to look for support to augment their understanding of the disability. Because participants felt that they needed additional knowledge and information regarding autism, they began to access supports to assist in this process. Supports that parents accessed included those that directly affected the child with autism as well as those that provided resources to family members.

One type of support that parents accessed was services to assist their child. Parents found it necessary at this time to ensure that services were in place for their child. This included services both inside and outside the home, depending on the needs of the child and the family as well as the comfort level of parents with the range of services that were available to them. Participants and their families accessed supports for their child with autism because they realized that their child had specialized needs and that they could not handle coping with this disability in isolation. A parent spoke of the decision to enroll her son in preschool:

> … from the time at the Glenrose … we were told well, special ed. preschools are probably the best place for him. … So we enrolled him in a special ed. preschool and I remember the interview at the school … (7f1).

Another parent whose child was not yet school-aged, spoke of accessing early intervention resources for her child:

> We had services in place for [our son] right away in '95. We had him in the GRIT program … (3m1).

While finding appropriate schooling, early intervention, or child care resources was important to parents at this time, some participants also indicated the need to put supports in place in their homes to assist them in managing and dealing with their child's behaviours and specialized needs. A mother spoke of her family's experience with in-home supports:

> So it was just sort of a gradual thing where we started getting more and more and more in-home relief to the point where her sleep was just really, really bad and we had to have people come in for overnight shifts. So we were at a point for relief where we were having people in the house for probably about five or six days a week (5f1).

Another parent agreed with the importance of having supports in her home:

> … I started a program with [Community Behavioural Services]. It was a very intensive program, everyday for two months. … At home we started ABA program about … three to four weeks ago. It makes a big difference and everybody notices that they only have to show him, to teach him something once (6f1).

During this stage participants also indicated feeling a need to access supports for themselves. There were differences indicated in the types of supports that people preferred as well as how each participant participated in such activities. Many parents spoke of the importance of reaching out to other parents that were experiencing the same types of difficulties as they were. A mother described her experience with support groups in the following way:

> ... they [Support Groups] were such an outlet for me. That we'd been carrying this weight around and finally talked about it with people. ... At least you knew that somebody knew what life was like (1f1).

Other parents agreed with the importance of connecting with other parents who shared similar experiences. One mother spoke of feeling energized as a result of having an outlet to discuss the challenges that she experienced in her life:

> ... I find that when I meet in the context of the group or go for coffee with a mom who has a child with autism, I find that it just kind of gives me that kind of boost I need just to go on and face the rest of my life (5f1).

The same parent talked further about the benefits that she felt as a result of talking with other parents:

> But certainly at that beginning time I think that it's so important and it was for me, to have to glom onto other parents in the same situation because it's almost like, you know, meeting other people from Mars or something when you've been just dropped down from the planet, you know. Because, I mean, you just feel so alien. And to meet another person with the same issues is just amazing. ... I remember going through ..., it was almost six months after [our daughter] was diagnosed that we were able to meet other people and I remember thinking that it was just the greatest thing in the world (5f2).

While some participants clearly felt that talking about their experiences with other parents was important to them, others were able to use support groups in a different fashion. Some parents indicated not feeling ready or comfortable sharing their experiences at this time, but felt that they still benefited from hearing the experiences of others. A father expressed the benefit that he received from attending Support Groups and learning vicariously from others' experiences:

> ... in some ways it was great because you saw women that were willing to share their feelings. So you could sit back and listen and you could say, "Yeah, that's how it felt." And ... it's very non-threatening. I can sit here and listen. And share things if I want. And I tended to do, my involvement tended to be in the process of running things. ... We went to the Autism Society Support Group a couple times. ... I found it really intimidating cause it was the first year and it was still really raw. ... I kinda got really intimidated by this ... cause the facilitator went around and made sure that everyone spoke their peace and whatnot. So you had no choice. ... So yeah, ... I know that it helps and I guess that was part of the healing process too, was to let it out and realize that ... with time it gets easier to share ... (3m2).

The same father discussed another situation apart from the context of the Support Groups that he felt assisted in his management of autism:

> And I tended to do, my involvement tended to be in the process of running things. ... That would be sort of where I jumped in. And when we'd have, you know, sessions where you'd have a person come in and talk about some aspect of life with a disabled child or whatever, ... you know, I felt that I can offer if I want, but quite often I get to listen and vicariously share in what's going on (3m2).

There were many participants that found it useful and an important part of dealing with their sense of loss to be able to attend support groups and other more informal contexts in order to share their experiences. In addition, hearing about others' experiences provided parents with some tools and suggestions in terms of how to deal with certain behaviours or concerns regarding their children.

The process of accessing supports for both the family and themselves afforded parents the opportunity to be in a better position to recognize the limitations that autism posed on their families. For example, a father described the limitations that his son placed on his family's social life:

> I think it's certainly true that if [our son] was not ... autistic, or if we didn't have [him] at all, our life would be very different. [He] ... wants to stay at home and ... he doesn't really like going out very much. And so ... we probably are much more housebound (2m1).

The above father's spouse agreed with the restrictions on their social life:

> ... [our son] has restricted my social life in particular. ... I found him ... impossible to take to people's houses because he would just cry and cry and cry the whole time and it is just awful (4f1).

A mother spoke of the challenges that her family faced as a result of her not being able to work outside the home:

> ...we are finding it very challenging at this point. A lot of it is the fact that I can't work. ... If [our son] was a typical child he would be in kindergarten a half a day a week and I still may not be working this year because of that (7f1).

As a result of having accessed supports and information as well as having their own practical experience and some understanding of what they would be facing, parents were able at this time to begin a process of incorporating the knowledge that they had regarding autism. They realized that their life as they knew it would have to change in order to facilitate a healthy adjustment to autism. They began to redefine their expectations as a result of this realization. The first set of expectations that were modified were those related directly to the child and his/her development. Expectations that parents had for their children had to be reconciled with the capabilities of the child. One mother describes this change as follows:

> I think I've come to terms with [the future], how we deal with life and how far ahead I look and my expectations. ... I guess I live more day to day. I used to be very future-oriented and ... it just challenged the core of your expectations. You have this idea about your life and you see your kids getting married and your kids graduating from school. Well, we're talking about even more basic than this, we're talking about expectations that my child will talk (5f1).

Another parent described the change in expectations in the following way:

> ... the expectations have completely changed too. ... My expectation now is a very base level of communication for [my son]. ... Your whole belief system and expectations change. The number one thing now is can you function and are you happy instead of whether you have a Ph.D. in nuclear physics or something (3m1).

In terms of reframing their expectations, parents also found it necessary to adjust their view of family. Not only did parents have preconceived notions regarding what their children's individual development would be like, they also had assumptions about the way that their family would be defined. Living with autism forced parents to make changes to the way that their family functioned. A mother described how her family had accepted that they would be different and that there were limitations that they had to adjust to with respect to her son:

> We find [our son is] coping a lot better, so probably there's two things happening. One is that we ... understand him so much better and we don't put him in highly stressful situations where he can bomb. ... Second, ... he's developing the skills to cope better in situations. We also came to a point where we realized that our family would be different (1f1).

A father discussed how his family life had changed as a result of having a child with autism:

> It affects absolutely every aspect of your life. You can't go to dinner with your family, you can't go on a holiday, like the thought of going to Disneyland - no way. We could take two of our kids but not the whole family. And so your whole concept of the family unit changes (3m1).

Participants indicated not wanting their family to change, but appeared to recognize the need to do so in order to be able to manage autism adequately. A mother spoke of her experience in this regard:

> This isn't what every family would do and this isn't what we envisioned our family doing. But this may be what our family has to do (1f1).

Lastly, parents identified changes to the expectations that they had regarding their personal goals. Many participants identified having career aspirations and other personal goals or ideals that they felt were necessary to rearrange as a result of the needs of their child:

> ... I planned before to become a teacher and I had to make a decision about my career because I graduated just a few months before I got the diagnosis. And I had to think seriously about ... my needs as a woman, as

> a mom. And I decided to use the knowledge and talent that I had to help this child ... (6f2).

Other parents were able to relate to having to make changes to their expectations regarding their careers. A mother stated of her experience:

> So the long term projection is that I don't know when I will be able to take a full time job which gives my husband all the stress of having to take care of the family (7f1).

Another parent spoke of having to redefine her expectations of herself as she had previously valued the importance of having control:

> ... I'm the kind of person that likes to ... oversee things and I think that having [our daughter] kind of made me more so. Especially where my kids are concerned. I like to know where they are and what they are doing and what is going on with them ... And I find that's been, I've had to relinquish part of that. That I don't always know what she's doing and I have to entrust in other people to keep her safe (5f1).

Stage VI: Going beyond Autism

The sixth stage identified by participants as part of the experience of raising a child with autism was making a decision to change the focus and not be solely defined by autism. Up until this point in the process, a large part of participants' focus had been on autism. Parents indicated that by this stage they had much of the knowledge, experience, and information that they needed to manage autism more adequately and nurture other areas of their lives. The choice to go beyond autism involved reconnecting with aspects of life with which they had previously lost touch as a result of the demands of parenting a child with autism. Going beyond autism also included a decision by parents to think about the future of their child and their family. By this stage, some parents indicated making plans for the future so that they had some peace of mind regarding what would happen to their child once they were no longer able to continue with their caregiving.

By this stage participants indicated feeling a need to go beyond autism. While much of their energies up until this point were focused on autism or on the understanding of the behaviours of their children, by this time they articulated wanting to make a change:

> But part of it was we said we are sick of grieving, we're sick of wallowing in our pity and our depression and everything else. Life is going to go on, we still have [our son] and we're not doing him any favours and we're not doing ourselves any favours by making our whole life stop because of autism. We've gone beyond autism so that was when we ... decided to have [our other son] ... (1m1).

Another participant stated:

> ... after about a year we got sort of tired of feeling crappy and said, "Let's get on with it." But it took a long time to do that (3m1).

There were two main reasons that parents chose to go beyond autism. The first was that participants needed to focus less of their energies on the management of autism than they had previously. Parents indicated having a better understanding of the disability by this time. A mother spoke of her experience in this respect:

> I go through periods of time, long stretches of time where I think oh yeah, ... things are rough and things are challenging with [my daughter], but I think that I'm more comfortable in the situation now and I've figured out enough things about it and I've figured out enough things about her where I don't feel like I need necessarily a huge support network anymore with her (5f2).

Another mother stated of the information that assisted her in moving on:

> ... probably the best thing to say about overcoming the grieving and just the ... inability to cope day to day ... I have to give to the amount that I read. Because I probably read about twelve books in six months, on autism. I've read just about everything on all the top ten lists and you know, it really helped just to get an idea, especially when the book spanned over childhood and into adolescence (7f1).

A second reason that parents chose to go beyond autism was for the sake of their other children, family members, and themselves. A large reason for the change in focus had to do with missed opportunities that they felt that other family members were experiencing. As well, parents reported feeling that it was unhealthy to focus on the needs of one member of the family to the neglect of others. A mother spoke regarding the impact that she felt her daughter's disability had on other children in the family:

> ...my other daughter was in the theater, was fascinated with the theater and always wanted to be an actress or go to the theater. And... she would say, "Oh, mommy, can we go to see this play or can we go to see this show?" And ... before I'd finish she'd say, "No, can't leave [my sister]." And [my other son], my youngest son, was very protective of [my daughter with autism]. ... And then one day there was a bit of an explosion. He was teasing my older daughter, you know. And I said, "Don't do that..." And he said, "Well, I don't count." He was twelve. He said, "[My sister] comes in, she bursts through the door and she's a great actress. [My other sister] ... demands all your time and I don't count." And we had to have a

> talk. ... And I realized that ... [I] was affecting the other children. I was damaging them in a personal way, in an emotional way. (8f1)

Another mother spoke of the need to regain a sense of balance in her life:

> I guess [my child having autism] has sort of forced my determination as far as the idea that we are not all going to be defined by autism and, that's not the only things we're going to talk about and that's not the only thing the kids are going to hear about. So we have balance. ... [We] still have the energy for all of our kids so that we don't feel that ... any one person in our family is getting a disproportionate share of others time and energy and stuff like that (1f1).

The extent to which families moved beyond autism varied among families as did the changes that needed to take place in order to be able to do so. For some families, the ability to move beyond autism and provide opportunities for themselves and other children included having the child with autism out of the home for periods of time. One family chose to access a shared-care situation which included their daughter being out of the home one to two weeks per month:

> ... [our daughter] has gone to a host family now for the last couple of years and we do a shared-care situation where she lives out of the house half of the time. ... For survival I really got to the point where I felt like I was going to crack and I couldn't keep up with it anymore (5f1).

The same mother described further the reasons for accessing additional respite:

> ... I think that if [our daughter] was living at home full time it would be very difficult to have a normal situation for our younger child. I think I've always wanted her to have a balance in her life where she's accepting of her sister and knows that [she] has a place in our family where she is your sister and she is my daughter and that doesn't change. Yet I also realize that she's five and she needs to do five-year-old things. ... And I don't want her to be resentful of her sister and I don't want her to have a life that is full of limitations because of it (5f2).

Decisions to go beyond autism tended to be fueled by both an immediate need to have some balance in the lives of participants as well as a need to begin thinking about the future of their family and their child with autism. A father discussed his worries in relation to the future:

> [My worries are] that a time will come in [our son's] life where we can't take care of him because we're too old or we're dead or whatever, and... the people who will be around him will not take care of him. I mean, it's as simple as that (2m1)

The focus on the future caused parents to go beyond autism by making plans for their child with autism. For example, a participant and her family chose to place their child with autism in a residential setting. A mother described her experience in this regard:

> ... I was being drained. ... We went to see a doctor ... and they had a special unit there for autistic children. Lovely little place. ... This was when our daughter was sixteen. They had this [place] and it was special for, they had a school and they had bedrooms, clothes drying on the line, a dog there, a rabbit. And we took her there to try her out. Anyway, after a month we went to see her. She seemed quite settled (8f2).

The same mother described her rationale for placing her daughter in residential care. While it was of benefit to her family in the present, it was also something that her family considered in order to have plans in place for her daughter's future. Of having her other children care for their sibling with autism she stated:

> You can't do that to your other children. That wouldn't be fair to them. ... Like I've said to my other children, "You can't have her cause you don't have room." And [our daughter] couldn't have her, she couldn't

> drag her around to all these [places] and she couldn't work. And [our son] couldn't. ... "But you must remember her birthday, her Christmas, check on her regularly." ... Which is what you would do with your sister who is normal. You wouldn't have her come and live with you. You have to think of normalcy. She's a forty year old woman, you don't live with your sister or your brother. In most cases, you don't. .... She's going to go somewhere. At this point we can change it and we can choose. It's a lovely place she's in, beautiful (8f1).

As a result of having begun to go beyond autism, participants reported feeling benefits in their lives. Due to an increase in time, energy, and knowledge, participants reported being able to now make choices that contributed to the preservation of all family members. A mother discussed how going beyond autism impacted her family:

> It's been a compromise that we've reached because ... when we make decisions in our family, I think we try to, instead of thinking ... necessarily of the child or the best interests of this member or that member. I think we try to keep everybody in the balance. ... I want to balance it somehow where all of us can come out at the end where there's some preservation here. Because I think to pour it all out into one child is not good, it's not good. Nothing good can come of it (5f2).

While family members, including spouses and other children, benefited from the decision to go beyond autism, parents also made the decision for their own well-being. A mother discussed her reasons for thinking of herself in the process:

> ... I also realized that it's a marathon, it's not a sprint, and I don't want to be an embittered, crusty old lady when I'm sixty, thinking about how I gave up my life so my child could have a life.

Another mother described the importance of maintaining a life outside of her son's disability:

> ... we both still try and have some friendships outside of the whole "a" thing, you know. ... It's a grip on the rest of the world because it's pretty easy to hibernate in your house (7f1).

The same mother described how this decision impacted her life:

> And at first I couldn't believe, I could go out for coffee. We could go out as a family and have a meal. ... I went home to see my parents who were quite aged at the time. Our life opened up (8f1).

The six stages of parenting a child with autism experienced by participants represent a process that takes place over time. Autism posed unique challenges in terms of its onset and developmental course that may not have been part of the experiences of parents of children with other disabilities.

V. DISCUSSION

These data illustrated a process in parenting a child with autism. The basic social process was a reframing of the vision of the child and the family. Because parents had certain expectations regarding what both their child's development and their family life should look like, parenting a child with autism involved bridging the gap between these visions and the reality of their situation.

The first aspect of reframing that took place for parents focused on the vision of the child. Parents had expectations of what their child's development would look like. As a result of the gap in their expectations and the reality of their child with autism, they chose to reframe their expectations to fit with the limitations and demands of their child.

A second component of reframing was related to the vision of family that participants had. Parents had a vision of what their family life would look like. The definition of family was challenged as a result of having a child with autism and learning the limitations that he/she posed on the family. Instead of completely changing their vision, parents chose to do certain things so that their family would correspond better with the original vision of what it should look like.

Within the main process of reframing the vision of the child and family, a sequence of stages emerged. Throughout these stages there were varying ways in which reframing happened. As well, there were certain similarities observed within existing theoretical literature as well as some differences as a result of specific challenges associated with parenting a child with autism.

Reframing the Vision of the Child

The beginning of parenting a child with autism was a time during which parents expected their children to be developing normally. They began to check their vision of what child development should look like by checking their expectations through a process of comparison. Since participants in this stage felt that their children were developing according to their vision, they had not yet begun the process of reframing.

The experiences of parents during this early stage in the process differs from what has been found in previous research (Bristor, 1984; Milgram & Atzil, 1988). This study provides support for the hypothesis that parents of children with autism have differing experiences than parents of children with other disabilities. Although there has not been a great deal of focus on the earlier stages of the process, what has been done tends to group multiple diagnoses in their samples (Frey et al., 1989) or focus on disabilities or handicaps which are present from birth (Bristor, 1984). For example, Bristor (1984) found the birth of a handicapped child to precipitate a major family crisis. This is not the case when parenting a child with autism. Since autism is not apparent early on, parents assume that they have a normal, healthy child. The detection of the disability early on is difficult (Siegel et al., 1988; Zoltak, 1986).

The next stage in the experiences of parents was one during which parents began to notice aspects of their children's development that were different and oftentimes, difficult to explain. This stage marked the beginning of participants' concern and worry regarding their children. As such, parents recognized for the first time the gap in their vision of their child and what they were experiencing.

The limited research that is available regarding autism in the early stages concurs with this experiences of parents in this study (Marcus, Kunce, & Schopler, 1997; Midence & O'Neill, 1999). For example, Midence and O'Neill (1999), conducted a grounded theory pilot study to better understand the experiences of parents of children with autism over time. They identified the early stage of raising a child with autism as one during which parents looked at their children's behaviour development and noticed aspects that were different and difficult to describe. As well, research by Marcus et al. (1997) noted that parents are able to suspect fairly early on that their child may have a significant developmental problem.

Once parents moved beyond noticing that something was different with their children's development, they began to seek out informal and then formal supports to assist in needing to know what was happening. By obtaining information regarding their children's difficulties and what they were dealing with, participants were able to begin to identify more clearly the gap between their vision and the reality of their children's development.

Although previous research does not identify the process of parenting a child with autism as one of reframing, there are certain similarities found in the reasons and the ways in which parents chose to obtain information regarding what they observed in their child.

Much of what parents noticed that caused them to seek supports included their children not fitting with their vision by not meeting appropriate developmental milestones as well as exhibiting odd, difficult-to-explain behaviours. Gray (1994) found similarities in the way that the process unfolded for parents of children with autism. For example, participants in his study identified the absence of language skills to be most stressful and the aspect of their child's development that caused them to seek medical attention. As well, Siegel et al. (1988), in their study of parents of children with autism, found similar results. They stated that of their sample, "98% cited concerns with language development, 84% cited concerns with social development, and 34% cited concerns with motor milestones" (p. 201).

The ways that parents accessed information in order to identify the reasons for the gap in their vision versus reality had similarities to Siegel et al.'s (1988) research. In this study parents used informal means of support before going to formal supports within the health care field. Siegel et al. (1988) also found the health care system to be of importance. Among their sample, "92% reported that their concerns had been discussed ... with their child's primary care physician (84% with pediatricians, 8% with general family practitioners). The remaining 8% of parents self-referred directly to other professionals" (p. 201).

Parents eventually received a diagnosis of autism. All identified this experience as one that was very difficult due to the vision that they had for their child being ripped away. As a result of having had the vision taken away from them due to the diagnosis, parents at this stage were not yet able to begin to reframe their visions of their children. They were able to identify that the vision that they had for their child was now gone. However, they were not yet ready to incorporate the diagnosis into a new vision.

Other researchers have identified this stage in the experience of parents of children with disabilities or chronic illness as a process called chronic sorrow. Olshansky (1962) was the first to introduce this concept. The literature with respect to chronic sorrow identifies that parents must make continual adjustments over time and that they experience sadness as a result of their child not fitting with their expectations. Ellis (1989) attempted to explain further the process of chronic sorrow by identifying the child with a disability as a distortion of the planned-for infant. His explanation fits well with the findings of this research.

Once parents learned that their child had autism and were able to mobilize themselves, they recognized that they must begin to understand this disability by obtaining further supports. The knowledge acquired by parents through obtaining supports assisted them in being able to close the gap between their vision of their child and the reality with which they were now faced. For the first time, parents were able to understand what they were dealing with. During this stage, parents reframed the vision of their child to fit with the reality of the limitations that autism placed on the child.

There have been similarities found in the ways that others have looked at this stage. For example, most theories related to managing disabilities have recognized the need to obtain post-diagnosis support to assist in this process. Chronic sorrow theories have identified the importance of social support (Davis, 1987). Other theorists using family adaptation and life management frameworks have also identified social support as integral in managing (Bristol, 1987; McCubbin, 1988; Scorgie et al., 1996).

Other similarities have been found with respect to the ways that parents are able to view their children following the diagnosis. For example, Midence and O'Neill (1999) identified parents as being better able to perceive and value their child's personality at this time.

Reframing the Vision of the Family

Reframing the vision of family does not take nearly as much time as reframing the vision of the child. As well, the focus on family reframing takes place later in the process. Until parents reframed their vision of the child and have a fuller understanding of autism, they were not yet able to focus on the family unit. This is because autism was the main focus of parents for much of the time in previous stages.

Because autism was at the forefront of the family for so long, participants identified having lost their vision of family life. As a result, after having much of the necessary understanding of autism, parents were able to begin to find that vision again.

The process of finding the vision of family involved parents making changes to their lives and making decisions that allowed their definition of family to fit with their earlier vision. Not much literature to date has focused on the ways that families define themselves in light of having a child with a disability.

In this study, the accessing of supports by parents assisted in their ability to allow their family definition to fit with their vision. For example, making use of respite services allowed parents to be able to participate in normal family activities. Gray (1994) stated that many participants "regularly used respite care services, which allowed them to lead a relatively normal life" (p. 293). Midence and O'Neill (1999) provided support for Gray's (1994) findings. In addition, Midence and O'Neill (1999) identified parents moving towards a normal vision of family by making plans for their child to be able to live an independent life at some point in the future.

The process of raising a child with autism involved a continual process of evaluating the expectations that parents had regarding their child and their family. Throughout the experience, participants attempted to make sense of their reality and become more comfortable in their situation by reframing their vision of the child and the family. This finding is different from those of other researchers and adds to our understanding of the experiences of parents when raising a child with autism.

Limitations of the Study

Limitations of the study related to the sample included the inability to conduct second interviews with two participants as a result of the participants having moved during the course of the study. It is possible that these participants may have provided additional information to support the findings of the research and thus, increase the generalizability of the findings. It is also possible that second interviews with these participants could have provided new information with respect to the experiences of parents.

A second limitation related to the sample was that a specific group of caregivers were interviewed. Many parents in this study were members of a support group for parents of children with autism. Individuals receiving support may be better adjusted than those dealing with autism without supports. Interviewing those not receiving support may have provided different information regarding the experiences of parents and the ways in which they manage.

The issue of data saturation also may have been a limitation in this study. Many participants were at or near the beginning of the process of raising a child with autism. As a result, there is limited information regarding the later stages of the process. The findings of Stage VI were compromised as a result of having interviewed only one participant who had experienced her child with autism having left home. Although the interviews with this participant were extensive, interviews with additional participants in the later stages would have improved the data saturation process.

Another limitation of the research was that all data were retrospective. Parents were asked to recall details of their experiences, sometimes over the span of several years. There may have been some difficulty in accurately recalling their experiences due to the passage of time.

Lastly, not as many males participated in the study as was initially anticipated. It was common for women to participate in the study as they are more commonly the parent responsible for the majority of childcare. However, in this study there were not observed differences in relation to gender. Males and females appeared to have similar experiences and tended to face the same types of challenges. Being able to interview more males would have assisted in the confirmation of this finding.

Conclusion

This study used a grounded theory approach to understanding the experiences of mothers and fathers over time in parenting a child with autism. Although additional research is needed, there were specific findings related to the experience of parenting a child with autism. The basic social process identified was a reframing of the vision of the child and the family. It appears that the unique characteristics of this disability may play a role in its detection and management.

Much of the previous research related to the understanding of autism and other disabilities has tended to focus on the parental experience of stress (Bristol & Schopler, 1983; DeMyer & Goldberg, 1983; Milgram & Atzil, 1988; Moes et al., 1992; Wolf et al., 1989). While parents in this study identified parenting a child with autism as being stressful at various points, there appeared to be other aspects to their experience in addition to stress. For example, the experience of reframing is central to parents' experiences and may be one way that they chose to manage stress. Examining parental experiences from this perspective allows a more positive understanding of how parents manage. Others have begun to view the experience of managing disabilities with this lens (Scorgie et al., 1996).

Further research in the area of autism would assist in developing a clearer understanding regarding how this disability is experienced by parents. For example, the possibility exists that the process of reframing is one way that parents manage the enormous amount of stress that they experience as a result of their circumstances. Future research exploring the relationship between reframing and stress would be helpful in better understanding the process that parents experience.

Another focus of further research could be the impact that autism has on the relationship between parents. This study did not provide details regarding the ways that this experience is negotiated between couples as well as the ways that it impacts on couples' relationships. Future research may want to focus on this area, especially given that much of what takes place for participants in terms of reframing the vision of the family tends to focus on the impact on other children in the family. Future research exploring other aspects of the family unit, including the impact on both couples and siblings, would be useful in better understanding the full impact of autism on the family.

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APPENDIX A

Call for Participants

Hello, my name is Susan Foley and I am a Masters student at the University of Alberta. I am conducting a study that focuses on the experiences that parents have when raising a child with autism. It is hoped that the results of this study will provide us with information about what it is like for parents who have a child with autism.

Both mothers and fathers who are raising a child with autism and are willing to talk about their experiences are asked to participate. An average of two interviews will be required, probably lasting for one hour each. The interviews will be tape recorded and later typed. Questions will be asked about parents' experiences in raising a child with autism. All interviews will be kept confidential and identifying information will not be used in the study.

Interviews will take place at a location that is convenient for you. I would be happy to come to your home to conduct the interviews. Once the study is complete, you will be given a final report that summarizes the findings of the research.

If you think you might be interested in participating or learning more about this study, please contact Susan Foley at 435-3595. She will tell you more about the study. If you should decide to participate, she will want to arrange a time for your first interview.

Thank you for your consideration.

APPENDIX B

CONSENT FORM

Parental Experiences in Dealing with Autism

INVITATION TO PARTICIPATE: You are invited to participate in this research because you are the parent of a child who has autism.

PURPOSE OF STUDY: The purpose of this study is to explore and understand the experiences of parents of children with autism over time.

EXPLANATION OF PROCEDURES: You will be asked to participate in two to three interviews that will be approximately one hour in length. During the interviews you will be asked questions about aspects of your experience in raising a child with autism.

POTENTIAL BENEFITS: Benefits to you include knowledge of the general results of the study and knowledge of the research process that you may acquire. Your participation in the study may help practitioners to determine better ways to assist families that are dealing with the challenge of raising a child with autism.

CONFIDENTIALITY OF DATA: Interviews will be tape recorded and transcribed. Names will be changed on transcripts to ensure confidentiality. Following transcription all audio tapes will be erased. All data will be stored in a secure place.

WITHDRAWAL FROM THE STUDY: Participation is voluntary. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

OFFER TO ANSWER QUESTIONS: If you have any questions, please feel free to ask. If you have any questions in the future you may call the investigator below. Thank you for your time and interest.

If you have any additional questions concerning the rights of research participants you may contact the University of Alberta Faculty of Graduate Studies and Research (492-3499).

PARTICIPANT SIGNATURE: ______________________

DATE: ______________

WITNESS SIGNATURE: _________________________
DATE: _______________

INVESTIGATOR SIGNATURE: ________________________
DATE:______________

INVESTIGATORS:
Dr. Norah Keating, (780) 492-4191
Susan Foley, (780) 444-2135
Department of Human Ecology

APPENDIX C

DEMOGRAPHIC QUESTIONS

Following are some general questions which will be used for research purposes. Your answers will be kept confidential. Please feel free to omit any questions that you do not wish to answer.

1. How old are you? ___________ years

2. How long have you been married? ___________ years

3. What is the highest level of education you have completed? (Please check one)

    ____ Less than high school

    ____ High school

    ____ Post secondary diploma

    ____ Bachelor's degree

    ____ Master's degree

    ____ Doctoral degree

5. How many children do you have? _____

    What is the age of your child with autism? _____

    What is the gender of your child with autism? ____________

    What age was your child when he/she received a diagnosis of autism?

_________ years

Has your child with autism developed language? (Please check one)

_____yes _____no

On a scale of 1 to 5 how would you rate the level of severity of your child with autism?

1	2	3	4	5
not severe	moderately severe	unsure/ no opinion	quite severe	extremely severe

If you have other children, what are their ages?_____________________________

How many of your children are still living at home? _____

6. Are you employed outside the home? YES ___ NO ___. If YES, are you employed

   PART-TIME? ____ FULL-TIME? ____.

7. Has your employment status changed as a result of your child's diagnosis with autism?

   YES ____ NO____. If YES, how?

____

____

What is your family's average yearly income? (Please check one)

_____ below $20,000 per year

_____ $20,000 to $40,000 per year

_____ $40,000 to $60,000 per year

_____ $60,000 to $80,000 per year

_____ $80,000 to $100,000 per year

_____ above $100,000 per year

APPENDIX D

Interview Guide for Second Interviews

Stage I: Expecting Normal

Were there any things about your first pregnancy that were different from your first?

You stated that the first year of your son/daughter's life was absolutely normal. What does that mean to you?

In our first interview you stated that you knew that your son's behaviour was unusual very early on. What made you feel that way?

What did you expect as a parent for your child when you gave birth?

I have talked with parents that stated that in the beginning they began comparing their child with the expectations that they had regarding what their child's development would look like. Can you tell me a bit about what you expected as a parent?

In our first interview you talked about feeling relieved when your daughter was healthy looking at birth. What caused you to be relieved?

Can you tell me a bit more about what caused you to believe that your daughter was autistic from birth? Do you think that this is knowledge that you now have looking at your experience in retrospect? Was there ever a period of time during which you thought she was developing normally?

Stage II: Worrying About Differences

Did you and your spouse both agree that there was something wrong at the same time? If not, how did your experiences differ?

In our first interview you spoke of one friend that you had that had tuned into something being wrong. Could you tell me more about that?

Parents have talked about a time during which they started noticing odd behaviours. How worried were you when you started noticing these behaviours in your child?
What caused you to become more seriously worried?
At what point did you start talking about your worries?

You mentioned in our first interview that your daughter was exhibiting some odd behaviours, including echolalia. How worried were you at that point?
What caused you to become more seriously worried?
At what point did you start talking about your worries?

You mentioned that when your daughter was a baby that people made comments to you about your parenting that caused you to doubt yourself. Can you tell me a bit more about that and what that was like for you?

Tell me about how you felt when others were not validating what you felt was wrong with your son/daughter.

Stage III: Needing to Know

You asked your husband to accompany you to the first appointment with the pediatrician. What caused you to believe that this was something serious enough that you needed him there?

Tell me more about the frustration that you said you felt when you took your son to the hospital and nothing happened. What was that like?

In our last interview you didn't mention much about others being involved in the process of your life with a child with autism. Could you tell me a bit more about who was involved, if anyone?

I have talked to parents who stated that they found it difficult to express to doctors what they were noticing in terms of their child's behaviours. Did you feel this? What was that like for you?

Stage IV: Having it Real

Tell me more about the assessment process. Who was involved and what was that like for you? Who was involved? What kinds of expectations did you have regarding the assessment?

You discussed a time following the diagnosis when you found it painful to be around friends. Can you tell me a bit more about that?

When you first received the diagnosis of autism, what did you expect that your life would be like?

You mentioned that shortly after the diagnosis you found it difficult to be in public places where you saw other children. Could you tell me more about that? What about these situations made them difficult?

Parents have also spoken of finding it difficult to be around other adults, including friends and family members, following the diagnosis. Did you have this experience? If so, what was it that made it difficult?

How important was it to you to have a diagnosis?

Many parents have talked about a time following the diagnosis during which they felt isolated and as if nobody understood their situation. You mentioned in our first interview that it was somewhat isolating for you. Can you tell me a bit more about what that was like for you? What made you feel as if others did not understand your situation?

Did it take some time for the reality of the diagnosis of autism to sink in?

Stage V: Taking Action

Tell me about your decision to access supports. What was that like? How did you get to a point where you were able to do that?

Tell me about the frustration that you said you experienced as a result of the changes that you have had to make in your life as a result of your child having autism.

Some parents have talked about getting to a point after the diagnosis where they redefined some of the expectations that they had regarding their child and family. Do you agree that that's something that you did? If so, how did you do that?

Stage VI: Going Beyond Autism

A theme that I have found in the interviews that I have done is that parents have certain expectations about what their lives will be like and they must integrate those expectations with the reality of their life with a child with autism. There seems to be a continuum on which people fall. Some have chosen to make major adjustments to their lives, while others seemed to have been able to maintain some sense of normalcy in their lives. You seemed to have been able to maintain a sense of normalcy in your life. Would you agree with that? If so, can you tell me a bit more about how you think you did that?

Many parents have talked about a time when they made a decision to move beyond autism and get back in touch with some aspects of normalcy. You mentioned doing this also. How did you do that? What were some of the reasons that you did so?

Some parents have talked about having less need for social support as time has passed. What was your experience with the need for social support?

What are some of your worries about your child right now?