

**EMERGING RESILIENCE IN A FAMILY  
AFFECTED BY AUTISM**

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**By**

**LORI JO-ANN MIERAU**

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## Abstract

The purpose of this phenomenological study was to examine the attributes conducive to the healthy adaptation of a family despite having a child with autism to gain a better understanding of autism and the effects of autism on family life. The study comprised a non-random sample of the whole four family members, which includes the child with autism. It is often the family as a whole that is greatly affected by the diagnosis and so all members of the family were deemed essential for the results.

Using a phenomenological framework, the study comprised data collected during semi-structured interviews with the four members of one family. The participants were interviewed in a three-step process to determine if qualities of resilience would emerge. Six themes evolved from the participants' interviews and were used to answer the research questions.

Interviews were transcribed and analyzed according to phenomenological procedures seeking the essence of a family's experience of raising a child with autism. The information gathered during the interviews clarified which factors contribute to the family's resilience. The researcher gained background knowledge of the guiding principles the family has used to overcome many of the challenges of autism. As well, direction and insight intended for other families with a child with autism were gained.

The contributing characteristics and attributes that emerged from the data were: acceptance and understanding; adaptability and flexibility; self-efficacy; strength and determination; and support from family or community.

The findings support the existing understanding of factors that contribute to resilience in families affected by autism. The data collected during the interviews

revealed that the participants share many of the same feelings of frustration, guilt and stress as other families affected by autism but also attain strength and a sense of hope or optimism for the future. Once the parents were able to move through the cycle of grief their healthy adaptation became apparent. The themes derived from the lived experiences of the participants demonstrate how they have emerged from adversity with resilience.

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## Table of Contents

Permission to use.....	i
Abstract.....	ii
Acknowledgements.....	iv
Table of Contents.....	v

### Chapter One: Introduction

Purpose of the study.....	Page 1
Research Focus .....	Page 2
Research Questions.....	Page 2
Significance of the study.....	Page 2
Limitations.....	Page 3
Operational Definitions.....	Page 4
Summary.....	Page 5

### Chapter Two: Literature Review

Overview.....	Page 7
Background on Pervasive Developmental Disorder and Autism.....	Page 8
History of Autism.....	Page 10
Etiology.....	Page 12
Co-Morbidity.....	Page 15
Diagnosis.....	Page 17
<i>Stresses Associated with Diagnosis</i> .....	Page 19
<i>Post Diagnosis</i> .....	Page 20
Resilience.....	Page 21
<i>Resilience and Autism</i> .....	Page 22
<i>Resilience and Family Life</i> .....	Page 26
Summary.....	Page 28

### Chapter Three: Research Design and Methodology

Purpose.....	Page 30
Research Design.....	Page 31
Selection of Participants.....	Page 32
Data Collection.....	Page 33
<i>Interview Procedure</i> .....	Page 34
Researcher-Participant Relationship.....	Page 37
Data Analysis.....	Page 38
Representing the Data.....	Page 42
<i>Researcher Interpretation</i> .....	Page 44
Trustworthiness.....	Page 44
Summary.....	Page 45

## Chapter Four: Results

Overview of Results.....	Page 46
Research Questions.....	Page 46
Introduction of Participants.....	Page 50
Presentation of Themes.....	Page 52
<i>Adversity and Stress</i> .....	Page 53
<i>Acceptance and Understanding</i> .....	Page 56
<i>Adaptability and Flexibility</i> .....	Page 59
<i>Self-efficacy</i> .....	Page 66
<i>Strength and Determination</i> .....	Page 73
<i>Support from Family or Community</i> .....	Page 77
Summary.....	Page 82

## Chapter Five: Discussion

Overview.....	Page 85
Discussion.....	Page 85
Findings.....	Page 86
<i>Researched Based Outcomes After Diagnosis</i> .....	Page 86
<i>Family Characteristics</i> .....	Page 88
<i>Familial Subsystems and Family Interaction</i> .....	Page 90
<i>Sibling relationships</i> .....	Page 93
<i>Parental contributions to inter-family relationships</i> .....	Page 94
<i>Spousal relationships</i> .....	Page 95
<i>Family accord</i> .....	Page 96
<i>Character Strengths to Overcome Challenges</i> .....	Page 97
<i>Social Support for Families</i> .....	Page 102
<i>Educational Support</i> .....	Page 106
<i>Benefit of Support System</i> .....	Page 106
Limitations of the Study.....	Page 108
Implications of the Study.....	Page 109
Extension for Research.....	Page 110
Conclusion.....	Page 111

Figure1. Emergence of Themes.....	Page 48
Appendix A: Diagnostic Criteria.....	Page 114
Appendix B: Ethics Proposal.....	Page 115
Appendix C: Interview Questions.....	Page 120
Appendix D: Support Services.....	Page 123
References.....	Page 124-134

## Chapter One

### Introduction

#### Purpose of the study

The purpose of this qualitative study is to analyze the emerging resilience in a family affected by autism. The researcher will attempt to make sense of or interpret this phenomenon from the rich descriptive data attained from the participants (Lincoln & Guba, 1985). Creswell (1998) explains, “the [qualitative] researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting” (Creswell, 1994, p. 255). Phenomenology is essentially the study of the lived experiences of the participants (van Manen, 1997). A phenomenological research design was chosen to draw conclusions about the participants to discover which attributes and characteristics the participants possess which attribute to their healthy adaptation of having a child with autism.

Resilience is the process of healthy adaptation despite adversity, trauma, tragedy, threats, or significant sources of stress (Masten, 2001). The concept of resilience includes not only the ability to withstand but also to rebound from a crisis (Heiman, 2002). Harris and Glasberg (2003) explain that some families of children with autism demonstrate an impressive sense of resilience and strength in their experience of raising a child with autism.

As a result of informal parent/teacher conversations before and after school, personal program meetings and observations of direct parenting style, it could be construed that the participants in this study have developed distinctive characteristics



which enable them to function cohesively within their family unit in spite of adversity. It is believed the participants in this study demonstrate determination, strength and flexibility in their parenting and life-style and were therefore worthy of further investigation.

### Research Focus

The researcher has been inspired to pursue this study in an attempt to explore the phenomenon of resilience in a family affected by autism. Some people cope well with stresses associated with parenting a child with autism and others do not. Some parents seem to handle life's disruptions while others struggle. One's ability to cope or to seemingly be resilient is an admirable quality and establishing the factors contributing to resilience is of great importance if others wish to emulate this success (Mundy & Sigman, 1989).

### Research Questions

Once the subject relevance was determined, the researcher determined the focus of the study on the following questions. These questions will be assessed and reviewed for analysis in chapter five.

1. What factors contribute to the resilience experienced by a family affected with autism?
2. In what ways did the family overcome the challenges of autism?
3. How or what can other families learn from the participants?

## Significance of the study

The motivation for researching the area of emerging resilience in families faced with this particular challenge results from personal experiences of the researcher observing many parents go through the trials of learning to deal with their child's autism. Boushey (2001) states that the experience of learning that your child has a disability is as distressing and devastating as experiencing a divorce or the death of a loved one. She explains the link between these three events is grief and suggests that it has a precise cycle that the parents must go through (Boushey, 2001). The cycle of grief is: shock, denial, guilt, isolation, panic, anger, bargaining, acceptance and hope (Boushey, 2001).

Through observation it would appear that the participants are in the final stage of grief: acceptance and hope. The participants in this study have been conceptualized as demonstrating a healthy adaptation, and are therefore worthy of exploration for further understanding. The emphasis of the study was the world of the participants and how they live it. This study has contributed to a more comprehensive understanding of the emerging resilience in a family affected by autism. This study is a journey from wonderment to awareness and recognition.

## Limitations

This study involves only one family affected by autism. A deliberate decision was made to do an in-depth phenomenological research format with only four participants for this study. A phenomenological study design allowed the researcher to gather valuable insight into the lived experiences of the participants. Although rich descriptive data was gleaned from the participants, a sample size of four will eliminate the possibility of generalizing the data. The circumstances of this particular family and

the findings derived from their interviews are context-bound and unique to this particular family and therefore have no global or widespread results. The findings are isolated with respect to this specific family.

A further limitation to this study is the fact that the researcher has taught both of the children interviewed in this study and in doing so has also come to know the mother quite well. It is not the intent of the researcher to obscure or influence any of the outcomes of this study. However, it is important to note that a preconceived perception of the family's healthy adaptation led to this research topic.

#### Operational Definitions

The following definitions have been provided to assist the reader with clarification.

*Autism:* A neurological, pervasive developmental disorder, which is characterized by impairments in communication, and social interaction and repetitive and stereotypic patterns of behavior (Saskatchewan Learning, 2007).

*Co-Morbidity:* Refers to two or more diseases or conditions existing together in an individual, coexisting or additional syndromes or diseases with reference to an initial diagnosis (Buckingham, Fisher & Saunders, 2003).

*Designated student:* A term used to describe students who have a disability falling under established criteria, which allows access to special funding and programming provided by the government to support their learning needs.

*Disability:* A physical or mental impairment that limits one or more of the major life activities of an individual (Rimmer, Braddock & Pitetti, 1996).

*Etiology:* Refers to the specific cause or origin of a disease, syndrome or abnormal condition (Mulhauser, 2007).

*Pervasive Developmental Disorder:* A group of conditions that involve delays in the development of many necessary skills which frequently involve communication and socialization (Fisher et al., 1999).

*Personal Program Plan:* This term is used to describe a living document that is produced in conjunction with parents and professionals for each designated student in the school system. It provides a plan of the student's individualized program within the school year (Saskatchewan Learning, 2007).

*Picture Exchange Communication System (P.E.C.S.):* was developed as a procedure to augment spontaneous communication in nonverbal children with autism (Quill, 2000).

*Special Education Teacher:* A role given to a teacher who specializes in programming and support for students with designated disabilities.

## Summary

Autism can be a difficult disorder to understand due to the diverse ranges of abilities for each individual but is generally characterized by a triad of impairments in socialization, communication and ritualistic behaviours (Bristol et al., 1996). Szatmari (2004) describes autism as the invisible disability. There are no facial anomalies or outward evident signs that a child is affected by this distressing neurological disorder (Webster-Heard, nd.). Bromley, Hare, Davison and Emerson (2004) explain that parents of children with autism are more likely to experience serious psychological distress than parents of children with other developmental disabilities. However, despite the many difficulties associated with autism, families can maintain a solid familial life style.

The following chapter will discuss the review of current literature available on autism and resilience for the purpose of exploring the affects of autism and the positive attributes and characteristics that foster resilience in families.

## Chapter Two

### Review of Related Literature

#### Overview

The following is a review of the literature on autism, a pervasive developmental disorder, and the effects of a diagnosis on families. Historical perspectives of autism will be investigated as well its etiology. Related behaviours of autism will also be discussed, as well as treatment and services for parents to consider when seeking behavioural intervention or programming assistance for their child.

In this chapter the subject of resilience as it relates to families affected by autism will be discussed. Resilience will be defined in addition to characteristics and skills that could attribute to a family's success. Although the view of emerging resilience in families affected by autism is a theme not well researched, there is extensive literature on the topic of autism, as well as its effect on the families. This chapter will focus on understanding these concepts within the same structure.

Often, families of a child with autism seem consistently distressed and anxious about aspects of everyday life. Other families with a child with autism have managed to overcome the constant challenges and trials of autism. Some families seem sheltered from the dissension associated with a life-altering diagnosis (Masten, 2001). In this chapter the researcher will explore literature on families that have overcome their challenges, attempting to discern which aspects of their lives can be emulated to achieve similar results for other families.

## Background on Pervasive Developmental Disorders and Autism

This section will define pervasive developmental disorder and specifically focus on the term autism as it is classified within pervasive developmental disorder. The Saskatchewan Learning document on Autism (1999) classifies autism as a pervasive developmental disorder, which is an umbrella term for disorders that involve impairments in reciprocal social interaction skills, communication skills and the presence of stereotyped behaviours, interests and activities.

Pervasive Developmental Disorders (PDD) have a common set of characteristics and include autistic disorder, Rett's disorder, Childhood disintegrative disorder, Asperger's disorder, and Pervasive Developmental Disorder not otherwise specified (PDD-NOS) (American Psychiatric Association, 2000). Pervasive Developmental Disorders (PDD) can range from a severe form called autistic disorder, to a milder form called Asperger's syndrome (Fisher et al., 1999). If a child has symptoms of either of these disorders, but does not meet their specific criteria the diagnosis is referred to as Pervasive Developmental Disorder not otherwise specified (PDD-NOS) (Fisher et al., 1999).

Other rare, very severe disorders that are included in PDD are Rett syndrome and childhood disintegrative disorder. All these disorders are characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotyped patterns of behaviour (Mundy & Sigman, 1989). For the purpose of this study this document will focus on autism specifically.

Autism is most often described as impairment in three distinct areas that include: communication and social interaction/relationships and restricted repetitive patterns of

behaviour (American Psychiatric Association, 2000). The symptoms and characteristics can manifest themselves in a wide variety of combinations from mild to severe (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001).

Autism is a multifaceted developmental disability that often appears during the first three years of life. Autism is widely recognized as a life-long neuro-developmental disorder that affects the functioning of the brain (Minshew, 1996). Autism affects each individual differently and to varying degrees. It is most often diagnosed in a collaborative manner by a team of specialists using specific diagnostic criteria, see Appendix A.

Most young children are social beings who need and want contact with others. They smile, cuddle, laugh, and respond eagerly to their primary care givers (Rodman, 2006). Occasionally, however, a child does not interact in this way. Instead, the child seems to exist in his or her own world. For the child with autism this world may be composed of repetitive routines, odd and peculiar behaviours, difficulties with communication, and a lack of social awareness or interest in others (Rodman, 2006). Parents are usually the first to notice unusual behaviours in their child and in some cases, they affirm that the baby seemed different from birth, unresponsive to people, or focusing intently on one item for long periods of time. The first signs of autism can also appear in children who seem to have been developing typically for a period of time (Bromley, Hare, Davison, & Emerson, 2004). When a typically developing toddler suddenly becomes silent, withdrawn, self-abusive, or apathetic to socializing with others, it is time to seek assistance from the medical profession (Bromley, Hare, Davison, & Emerson, 2004).



Research has shown that parents are usually correct about noticing developmental problems, although they may not realize the specific nature or degree of the problem (Rodman, 2006). Children typically communicate to access what they want and to avoid what they do not want (Halle, 2005). These are functions of early communication and when children fail to communicate clearly enough to meet these functions, they may resort to the challenging behaviours that often accompany autism because they assume the behaviours have a communicative function (Halle, 2005).

The Center for Disease Control and Prevention (2001) suggest assessment and diagnosis should involve an experienced multi-disciplinary team. For now, there is no cure for autism. There are, however, highly effective treatment and intervention methods available that can help individuals and their families manage this disorder (Dunlap & Fox, 1999).

Many children with autism can learn to communicate effectively and share in family life and the majority will attend school with varying degrees of support or specialized programming (Sivberg, 2002). Currently, children with autism are seldom institutionalized, however, historically a diagnosis of autism meant the child was institutionalized (Whitman, 2004). This was considered best practice in the belief that a suppressed environment, in which social experiences could be restricted, was necessary to control the atypical behaviours of the child with autism (Whitman, 2004).

### History of Autism

In 1943 Dr. Leo Kanner of the John Hopkins Hospital studied a group of eleven children and introduced the label early infantile autism into the English language (Janzen, 1996). Kanner (1943) based his findings on eleven children with autism who were

referred to his clinic and those attending a particular special school. He made no estimates of the numbers in the general population, but thought that this syndrome was rare (Wing, 1993). The word autism originated from the Greek word *autos*, meaning self, implying narrow relationships with others (Janzen, 1996). Kanner (1943) observed that these children were socially withdrawn, preoccupied with routine, and struggled with spoken language, yet often demonstrated capabilities not consistent with learning disabled children. They also did not fit the patterns of emotionally disturbed children (Kanner, 1943).

In 1944, Dr. Hans Asperger applied the term autism to children who were socially awkward and had developed some extremely unusual behaviours but were obviously very bright (Wing, 1993). Asperger (1979) identified behaviour and abilities that he called autistic psychopathy, meaning autism (self) and psychopathy (personality disease). This pattern included a lack of empathy, little ability to form friendships, one-sided conversation, intense absorption in a special interest, and clumsy physical movements (Asperger, 1979). Asperger called children with autism little professors because of their pedantic desire to discuss their favourite subject in great detail (Asperger, 1979).

In the mid forties, the study of autism shifted its focus from a behaviour disturbance characterized by a collection of peculiar behaviours, to that of a disturbance caused by poor parenting style (Wing, 1993). Therapists began to put forward the notion that children were not born autistic, but became that way as result of poor parenting style (Wing, 1993). In the absence of any biomedical explanation for what causes autism after the behaviour symptoms were described, psychologist Bruno Bettelheim, and other leading psychoanalysts of the era, embraced the notion that autism was the result of

mothers who were cold, distant and rejecting, and that children were thus deprived of the chance to bond properly (Bettelheim, 1967). Bettelheim's theory was immensely popular, despite the fact that Dr. Kanner had described the children with autism as not fitting the patterns of the emotionally disturbed (Kanner, 1943). Nevertheless, Bettelheim became a leading public figure on autism until his death, when it was revealed that his research results were greatly exaggerated (Hibbs & Jensen, 2005).

Turnbull and Turnbull (1990) explain that it was typical for professionals of this era to refer to parents of a child with autism as rigid, perfectionistic, emotionally inept and depressed. The term refrigerator mother was often used as a label for mothers of children with autism (Simpson, Hanley & Quinn, 2002). Simpson, Hanley and Quinn (2002) explain that these mothers were often blamed for their children's atypical behaviours, which included rigid rituals or routines, speech difficulty, self-injurious and self-isolation. Labeled refrigerator mothers, they were told that their cold mothering style had traumatized their infants when the lack of mother/child attachment was in fact due to the lack of social reciprocity in the children rather than the mother's ability to bond (Simpson, Hanley & Quinn, 2002). To label the mothers as refrigerator mothers was an extreme disservice. However, this theory was embraced by the medical establishment and went largely unchallenged into the mid-1960s (Hibbs & Jensen, 2005). Its effects have lingered into the 21st century (Hibbs & Jensen, 2005). It has been difficult for some parents to overcome this form of labelling (Simpson, Hanley & Quinn, 2004).

## Etiology

Until recently, the question of what causes autism has been highly controversial (Rapin & Wing, 1988). We know that autism is a neuro-developmental disorder with

genetic and environmental etiologies (Fatemi, 2002). It is agreed that the presence of autism is not related to parenting style, social economic status, race or ethnicity (Ruble & Brown, 2003). Scientists are exploring the neurological, biological and genetic factors associated with autism and most experts will concur that autism is probably caused by a combination of genetic and environmental factors (Whitman, 2004).

Researchers at the McMaster Children's Hospital in Hamilton, Ontario have made a recent discovery (Abraham, 2007). Canadian scientists are confident that they are close to finding the link or genetic markers of autism. This is a breakthrough that could revolutionize how the condition is both detected and treated (Abraham, 2007). The researchers have located at least five areas of the genome that harbour genes linked to autism susceptibility, including those crucial for brain function (Abraham, 2007).

Researchers indicate that the DNA testing for autism would enable physicians to improve the process of diagnosing autism (Abraham, 2007). Thus, early detection will increase the opportunities for intervention strategies, which will assist families in mitigating the worst effects of autism (Abraham, 2007). Doctors currently rely on psychological tests to diagnose autism in children at age two or three, but a DNA test could identify those affected as babies, or perhaps even before they are born (Szatmari, 2004). Obtaining an early diagnosis and understanding more about the origin or genetic markers for autism will assist parents with coming to accept the diagnosis. Consensus among professionals is vital for parents (Bristol et al., 1996).

Researchers agree that autism results from multiple etiologies and is likely present during early infancy (Ruble & Brown, 2003). Whitman (2004) illustrates autism as “a neuro-developmental disorder with genetic underpinnings that lead to the brain failing to

function properly” (Whitman, 2004, p.140). Studies reinforcing the genetic link have focused on the incidence of autism in twins, noting a higher rate of autism in identical versus fraternal twins (Folstein & Rutter, 1978). Szatmari and Scherer from McMaster University, using new genome scanning tools, have discovered several different autism-related genes that can play a role in different families (Abraham, 2007). The combination of environmental factors and genetic links help to clarify why no two children, not even identical twins, have identical symptoms (Abraham, 2007).

In other studies, researchers are using magnetic resonance spectroscopy (MRS) to examine whether the normal processes of synaptic pruning and programmed cell death (apoptosis) in early child development carry on normally in children with autism (McIntosh, 1998). A breakdown in this process could lead to an enlarged brain and researchers are looking for changes in the levels of N-acetylspartate, which provides a measure of neuronal density, and choline, creatine and lactate which can be used to measure membrane breakdown (McIntosh, 1998). By comparing the differences in the proportions of these brain chemicals between children with autism and those of typical children, researchers will be able to determine if the apoptosis and synaptic pruning are indeed a link to helping to determine the cause of autism (McIntosh, 1998).

The incidence of autism is ever increasing, but the increased number of children with autism is more likely to be reflecting the practice of a broader definition of autism, changes in diagnostic criteria and improved recognition of autism in children (Ruble & Brown, 2003). Epidemiological studies are still in the early stages in Canada and more surveillance and research are needed to develop accurate data on the prevalence of autism

but it is estimated that one in every two hundred children in Canada is diagnosed with autism (Autism Society of Canada, 2007).

Since the current diagnostic criteria are in terms of descriptions of behaviour, it is sometimes difficult to diagnose (Wing & Potter, 2002). The possibility of new DNA testing could help to identify those affected as babies or even before birth, which would allow parents to make informed decisions prior to birth (Szatmari, 2004). Szatmari (2004) explains that identifying children with autism early is vital to counter autism's worst effects. The earliest criteria, suggested by Leo Kanner in 1943, were very narrow and Wing and Potter (2002) suggest that the current incidence of autism in the general population has increased to as many as one per two hundred children and may be rising.

#### Co-morbidity

Due to limited information of biological markers for a diagnosis of autism, a clinician must have specialized skills and experience in identifying the behavioural disorders associated with it to make appropriate referrals (Ruble & Brown, 2003). Abnormal behavioural symptoms in people with autism have been viewed by many professionals as key components of autism and may result from their inability to cope with the environmental demands and physical discomfort (Tsai, 1996). There is a growing body of research which links autism with disorders such as anxiety disorders and obsessive-compulsive disorders (Quill, 2000).

Other areas of co-morbidity related to behavioural symptoms include: a) hyperactive-inattentive cluster symptoms; b) tics, Tourette syndrome, and movement disorder symptoms; and c) compulsive repetitions, explosive/self-injury symptoms and mood disorder symptoms (Bailey, Simeonsson, Winton et al., 1986). Behavioural issues

may manifest into biting, hair pulling, smacking, and fecal smearing (Leitch, 2005). The only specifics that can be said to be a symptom of autism are those found on the diagnostic criteria; therefore, anything not in the diagnostic criteria is considered to be co-morbid (Leitch, 2005).

Hill and Furniss (2006) assessed children with autism and compared them with a matched control group to determine if children with autism were more likely to experience emotional and behavioral disturbances than their peers. Individuals with autism were found to have a significantly higher occurrence for behaviour disorders such as organic disorder (mental illness that results from a physical cause), mania (mental disorder that involves extreme optimism and excessive energy, often accompanied by uncontrollable irritability and anger), anxiety, self-injury, eating and sleeping disorders, impulse control and depression (Hill & Furniss, 2006). Hill and Furniss (2006) clarify that it is difficult to resolve whether the differences between autistic and non-autistic groups reflect specific patterns of co-morbidity or simply reflect greater generalized behavioural disturbance in persons with autism. In a similar study, Spence (1997) noted that the most significant behavioural manifestations of autism are: separation anxiety and obsessive-compulsive disorder. Therefore, the core characteristics of autism including repetitive behaviours, difficulties in social relationships, and altered mood contribute considerably to the abnormal behavior of children with autism (Hill & Furniss, 2006).

Pharmacotherapy is often used in the management of autism to improve behavioural symptoms that hinder the patient's ability to participate in educational, social, work, and family systems (Hibbs & Jensen, 2005). However, no single therapeutic agent is appropriate for the treatment of all children with autism (Hibbs & Jensen, 2005).

## Diagnosis

Parents often struggle with guilt when considering the delayed development of a child with a disability (Rutter, 1978). Bromley, Hare, Davison and Emerson (2004) explain that parents of children with autism are more likely to experience serious psychological distress than parents of children with other developmental disabilities because autism is a complex and difficult disability to understand. With other diagnoses, professionals are able to educate parents and care givers and can often provide a comprehensible prognosis for the future of the child. However, because the outcome for children with autism is so diverse, professionals are somewhat averse to providing conclusive or definitive results for the child (Baron-Cohen, 1995).

Doctors and experts still do not know everything there is to know about autism (Dunlap & Fox, 1999). This is in opposition to the parent's needs; parents want to know everything they can about their child's disorder (Sullivan, 1997). The risk of negative influences due to a child's autism may be heightened for the family because of the ambiguity of the child's disorder and the uncertainty of the prognosis (Bristol et al., 1996). As well, a lack of consensus among professionals about the best treatment for children with autism can be cause for additional stress and parental confusion (Whitman, 2004).

Parents are disoriented as to which treatment will best assist their child and there are a number of treatment options to consider (Whitman, 2004). Interventions available include: alternative communication programs, speech and language therapy, occupational therapy, physical therapy, play therapy, behaviour reduction strategies, and biomedical treatments such as pharmacological, anti-yeast, homeopathic alternatives, immunology,



vitamins, diet, and craniosacral manipulation (Whitman, 2004). Early intervention programs, support services and accessibility to adequate health services for families have been identified as vital for parents learning to live with autism (Thomlison, 1997). The primary goal of interventions for children with autism should be to enhance their social and communicative development (Quill, 2000). The parents of a child with autism may endure pressures associated with strained family relationships due in part to cost of therapies needed for their child. Parents of children with autism should strive to seek knowledge and increase their understanding of autism in order to make informed choices for costly therapies (Baron-Cohen, Allen & Gillberg, 1992).

Human beings try to make sense of stressful events by searching for explanations and meaning (Dale, Jahoda & Knott, 2006). Yet the information about autism remains almost as puzzling and fascinating today as it was when first recognized more than sixty years ago (Lawson, 2006). In the past twenty years, the attitudes towards children with autism and their families have changed significantly (Sivberg, 2002). Marcus, Kuncze and Schopler (1997) attributed this paradigm shift to the perception of autism as a developmental disorder rather than as an emotional disturbance or mental health disorder. Current research about autism has had a positive impact in public awareness of the disability (Dale, Jahoda & Knott, 2006). Parents are no longer viewed as the cause of their child's disorder. In recent years, parents are more often viewed as advocates. Steps for successful advocacy include: increasing awareness, understanding the details of legislation and identification of private or corporate support (Montgomery, 2007). Parents have the ability to be an influential component to the treatment and programming for their children (Sivberg, 2002).

### *Stresses Associated with Diagnosis*

There are many family pressures associated with a diagnosis of autism. Turnbull and Turnbull (1990) point out that whatever the lived experiences of one family member are, they affect or influence all other members in the family unit as well. For the family with a child with autism, lack of social assimilation or ability to fit in can cause turmoil (Krausz & Meszaros, 2005). Krausz and Meszaros (2005) explained that the impact of a severe disability is never restricted to just the individual with the disability but for all of the immediate members of the family as well. When a family with a child with autism attempts to go out in public, the other members of the family may be embarrassed if the child exhibits strange behaviours typically associated with autism (King, Zwaigenbaum, King, & Baxter, 2006).

Many uninformed people in society still tend to blame the child's parents for these unusual behaviours. Public demonstrations of problem behaviour can cause some parents to isolate themselves as a defense mechanism (Miller & Sammons, 1999). According to Dunlap and Fox (1999) "the juxtaposition of the child's physical typicality and extreme behavioural deviance can make a parent's sense of humiliation even more acute" (Dunlap & Fox, 1999, pg. 3), thus compounding the parent's isolation.

Parents of children with autism have many stresses related to the diagnosis. In fact, sometimes even obtaining the correct diagnosis can be onerous (Sivberg, 2002). The fact that there are no best options for treatment that work for all children with autism, and that diagnosis is often delayed because the predictors of prognosis are uncertain, compound the stress related to the diagnosis process (Dale, Jahoda & Knott, 2006).

Human beings try to make sense of stressful events by searching for explanations and meaning (Dale, Jahoda & Knott, 2006).

Stern and Bruschweiler-Stern, (1998) explain that the experience of being told that something is wrong with your child is unpredictable and emotionally unimaginable. Upon hearing the diagnosis, parent's hopes and fantasies for their child are suddenly shattered (Boushey, 2001). Parents are instead held prisoner in an enduring present (Stern & Bruschweiler-Stern, 1998). Most prospective parents are excited about the task of planning for the future but the birth of a child with a disability may create both positive and negative reactions (Alper, Schloss & Schloss, 1994).

### *Post Diagnosis*

Despite the negative impacts of the past association with autism research, tremendous growth in public awareness of the disability has prevailed (King, Zwaigenbaum, King & Baxter, 2006). Once parents are able to move past the cycle of grief, they can become an advocate for their children (Boushey, 2001). The grief cycle is a natural process when one experiences a loss and parents of the child who receive a diagnosis of autism go through the cycle due to the loss of the hopes and dreams that they had for their child (Naseef, 2006). A parent of a child with autism states: "things become blurry after this devastating news. You continue to function, but you don't know how you do it or later remember the details" (Boushey, 2001, p. 2). The process of acquiring a diagnosis such as autism is often likened to bereavement (Dale, Jahoda, & Knott, 2006).

The impact of autism presents huge challenges to parents and caregivers. Some life changing issues identified by parents include the child's resistance to change, the child's disparaging conduct and behaviours, sibling's ability to manage difficulties within the

family dynamics and the parent's sense of isolation (Miller & Sammons, 1999). Families are also concerned with communication, education and related services, relationships with professionals and the independence of the child and his/her future concerns (Bristol, 1984). The chronic nature of autism can be draining to some parents and there is a risk of parents becoming exhausted (Bristol, 1984).

Parental distress over factors such as intensity, magnitude, duration and the unpredictability of this disorder contribute to the burn out rate of parents (Wolf, Noh, Fisman & Speechley, 1989). Parents of children with disabilities experience greater stress and a larger number of caregiver challenges, such as more health problems, greater feelings of restriction, and higher levels of parental depression than parents of non-disabled children (Quine & Paul, 1985).

Bromley, Hare, Davison and Emerson (2004) completed a quantitative study in which they interviewed sixty-eight mothers children with autism. They found that half of the mothers screened positive for significant physical distress associated with their parenting and life-style. They also noted there was a direct correlation between physical distress and a lack of family support (Bromley, Hare, Davison & Emerson, 2004). Some parents described the process of coming to terms with diagnosis as painful, encompassing feelings such as shame, guilt and self-pity (Dale, Jahoda & Knott, 2006). Not all families affected by autism are impacted negatively. There are families who demonstrate a healthy adaptation or resilience despite the adversity of parenting a child with autism.

## Resilience

The definition of resilience differs slightly among researchers; however, the commonality among definitions is an individual's ability to lead a more successful life

than expected due to the presence of adversity (Brooks, 1994). Resilience is a person's capacity to navigate through life well regardless of harsh conditions or misfortune (Alvord & Grados, 2005). Masten (2004) describes resilience as a "class of phenomena characterized by good outcomes in spite of serious threats to adaptation or development" (p. 228). It can be described as a sense of competence in the context of significant challenges to adaptation or development (Ungar, 2004). Luthar (2000) describes resilience as a dynamic process encompassing positive adaptation within the context of significant adversity. Resilience can also be defined as a positive end of the distribution of developmental outcomes among individuals at high risk (Rutter, 1990). Gordon (1995) defined resilience as the ability to flourish, mature, and increase ability and skills in the face of adverse situations. Families of a child with autism are faced with a great deal of adversity in their daily lives. When they rise above these challenges and continue to develop a healthy adaptation despite their difficulties they can be considered resilient.

### *Resilience and Autism*

Resilience within families affected by autism is not a well-researched area yet this phenomenon does exist. The question of why some people cope well with stresses and others do not is a fascinating concept. Some parents seem to handle life disruptions in stride while others falter (Heiman, 2002). One's ability to cope or to seemingly be resilient is an admirable quality and identifying how they do this is of great importance if others wish to emulate their success (Mundy & Sigman, 1989). It is important to identify elements that enable families to cope effectively and emerge from a crisis or persistent stress. Resilience does emerge in some parents of children with autism (Heiman, 2002).

Discovering which aspects of their attributes and characteristics that can be emulated are vital for families.

Many families with a child with autism have managed to overcome the constant challenges and trials of having a child with autism. Ungar (2004) describes a constructionist approach to resilience as the outcome from negotiations between an individual and his/her environment in which the individual remains healthy amidst conditions which are collectively viewed as adverse. Families that include a child with autism can be viewed in this context. A diagnosis of autism would collectively be viewed as an adversity to cohesive family life. The family's ability to remain healthy and cope with such adversity contributes to their resilience. Ungar (2004) explains that "researchers of resilience continue to conduct studies in the hope of revealing ways to inoculate children against personal, familial, and environmental acute and chronic stressors" (p. 342-3). Ungar (2004) clarifies that the constructionist's view of resilience is that the factors are unique to each individual and their social grouping and that the challenges are relative to the lived experience of the individuals. This is of particular interest when investigating resilience within the subject matter of autism, as the experience of each family affected by autism will be unique with exclusive entities.

Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats, or even significant sources of stress (Masten, 2001). Stress is often associated with family and relationship problems, serious health problems, or workplace and financial stressors (Masten, 2001). The concept of resilience includes not only the ability to withstand but to also rebound from a crisis (Heiman, 2002). Harris and Glasberg (2003) explain that several families of children with autism demonstrate an impressive

sense of resilience and strength in their experience, learning to balance hard demands with grace and humour.

O'Brien (2007) attributes resilience in families affected by autism to flexibility. Learning that your child has a lifelong developmental disorder is stressful and challenging to any family, yet it is clear that some families adapt and adjust more readily than others and their resilience comes from their malleable qualities and learning to live with uncertainty (O'Brien, 2007).

Resilient parents of a child with autism invariably seek to develop the necessary skills to deal with their child's atypical behaviours. To succeed or to surpass the risk associated with adversity a person must draw upon all of his or her resources: biological, psychological, and environmental (Gordon-Rouse, Longo & Trickett, 2006). Resilient parents of children with autism achieve this goal.

Resilience can emerge with support and proper intervention (Sivberg, 2002). Appropriate intervention can help to mitigate the likely feelings of guilt and vulnerability associated with diagnosis (Stern & Bruschweiler-Stern, 1998). Family members can be encouraged and their sense of order or control can be re-established with assistance from community, extended family, and friends (Naseef, 2006). In a qualitative case study, Dale, Jahoda and Knott (2006) determined that mothers who felt that they were solely responsible for their child with autism suffered from feelings of isolation and depression. They also concluded that the role of social supports available to the family significantly contributed to the mother's reduction in stress. Social supports that were deemed useful included counseling for parents and their children and early intervention programs for the child with autism (Dale, Jahoda, & Knott, 2006).

Families of children with autism are faced with great challenges (Herman, 1992). Parents of children with autism are inundated with difficult and persistent problems in parenting (Dale, Jahoda & Knott, 2006). Heiman (2002) conducted a qualitative study and interviewed thirty-two parents of children with autism, and determined that “families either adapt flexibly and mobilize into effective action or freeze in various degrees of rigid, ineffective reactions, whereas others tend to resist or even deny the diagnosis itself” (p. 160). Families of a child with autism face many challenging circumstances, and often for even the most mundane daily life tasks (Sivberg, 2002). Sivberg, (2002) inferred that a strong sense of cohesion would assist parents to better cope with their daily tasks in parenting a child with autism. Difficulties encountered by parents raising a child with a disability are anxiety, overprotection, rigidity, low levels of family coherence and less emphasis on the personal growth of other family members (Margalit & Heiman, 1986).

Psychological characteristics of the parent, such as, perceived self-efficacy, one’s ability to positively handle stress and coping strategies, are attributes that will assist in developing a strong sense of accomplishment and well being (Dunn et al., 2001). Heiman (2002) lists the contributing variables of resilience as, successful adjustment in terms of self-esteem, social support, problem solving skills, well-defined faith, coping skills, interdependence and the ability to reframe barriers and obstacles. These characteristics enable parents to function and to maintain their morale and optimism during times of crisis and to cope in a productive way (Heiman, 2002).

Families of children with autism can be some of the strongest, most vibrant people. Moreover, it is their healthy adaptation that will prove to be one of the greatest prevailing resources for their children (Dunlap & Fox, 1999). Regardless of how many



professionals are involved with the child, the most influential and significant effects will be achieved by the child's family (Alper, Schloss & Schloss, 1994). Families are truly instrumental in the growth and development their children with autism achieve. The extent to which a child and his or her family can meet everyday challenges can predict the ultimate outcome for the child as well as for the other family members (Dunlap & Fox, 1999).

### *Resilience in Family Life*

Various strategies have been highlighted in the current research to assist with the stress of parenting a child with autism. Sivberg (2002) analyzed survey results from parents of typical children and parents of children with autism. Sivberg (2002) suggests that maintaining a keen sense of family coherence has a powerful stress reducing effect on parents of a child with autism. Sivberg (2002) concluded that parents should strive to achieve two specific dimensions of cohesion within their family: a) comprehension or the constant pursuit of knowledge associated with autism; and, b) the development of manageability of the child's disorder, specifically the ability to manage abnormal behaviours. Heiman (2002) highlights the importance of social resources and the need for effective programs of intervention.

In the time following the diagnosis, educators need to be sensitive and considerate towards the family (Kluth, 2003). Professionals need to be cognizant of the stress and anxiety associated with a diagnosis, and need to be respectful of the observations and interventions that parents have found successful (Kluth, 2003). Parents should be the educator's first source of knowledge when teaching a child with autism (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001). Parents know their child best and can offer valuable

strategies to assist with their child's needs (Dunlap & Fox, 1999). Parents can be empowered by sharing their skills and knowledge proven to be successful. As well, encouraging them to gain the confidence to do some problem solving on their own can be conducive to a healthy home life for the entire family (Bailey et al., 1986).

For the child with autism, their family will be their life-long support system so empowering the family members will allow them to create balance and understanding within their family unit (Dunlap & Fox, 1999). Educators should be accommodating and supportive in regards to the family's need for practical information. Even though the effects of diagnosis might be most disorienting for families immediately following the diagnosis, a family's need for support is longitudinal (Rutter, 1978).

Families need to acquire knowledge and skills to build confidence and competency when problem solving (Bailey et al., 1986). When families are coping well, so are their children with autism. Families need to feel a sense of control (Dunlap & Fox, 1999). A fundamental skill that families need to help their children to acquire is the ability to interact in a functional meaningful way and to be able to communicate his/her wants and needs (Kluth, 2003).

Families need to access support for the behavioural concerns for their children as well. The availability of a strong support system can assure a more positive familial impact (Alper, Schloss & Schloss, 1994). Issues such as self-mutilation or aggression towards others are behaviours which must be modified (Mundy & Sigman, 1989). The ability of parents to interact with their child in a pleasant and productive manner is crucial. Training family members to work with their children rather than relying on trained clinicians has numerous benefits (Hibbs & Jensen, 2005). Hibbs and Jensen

(2005) suggest that it is more effective for the child, satisfying for the family, more cost effective, and gives the family the flexibility that is vital to programming for a child with autism. Once parents develop these necessary skills, they can pass on the information to teachers, care givers and extended family members (Singh, et al., 2006). Hibbs and Jensen (2005) caution, however, that although parent training has proven to be an excellent resource, there are limitations such as: problems in generalizing strategies to other unique children and the effectiveness of the parent's training. Children can become extremely dependent upon their parent as a treatment provider and therefore may continue to exhibit limited self-directed responding (Hibbs & Jensen, 2005).

The siblings of children with autism also need support and guidance. Harris and Glasberg (2003) point out that it is important to recognize the difference between the normal frustration of childhood and the special impact of having a sibling with autism, explaining that siblings need information on autism and its impacts, assistance in coping with anger and other emotions, and the skills to play or interact with their special siblings.

The behavioural needs of the child with autism are complex and can often cause disruption in the family's daily routines. Parents often feel exhausted, frustrated and socially isolated (Dunlap & Fox, 1996). Access to programs and support staff who can assist with behaviour modifications can ease some of these stresses and this assistance can be vital for the family's sense of congruency (Sivberg, 2002).

## Summary

The trials of parenting a child are great, the trials of parenting a child with autism are truly immense and transcend most of our imaginations (Sivberg, 2002). Most parents

and families with a child with autism live in constant hope that treatments, programs and resources will evolve that will have a positive impact on the quality of life for their children (Wheeler, Baggett, Fox & Blevins, 2006). Amy Lenhard-Goehner, mother of a son with autism states: “The challenges of this world are greater, but the accomplishments - those firsts - are that much sweeter” (Time Magazine, April, 2002, p. 45). Jim Boudier, father of a son with autism explains that despite the difficulty in raising a child with autism, he is convinced that any parent can find the love in his or her heart required to do such a task; despite all of the barriers, the parent will have his or her love returned and multiplied a hundred fold (Boudier, nd.).

The first research question asks which factors promote resilience. According to the literature researched, the factors that may help parents to moderate the high-risk effects of autism are: a) flexibility, b) problem solving, c) patience, d) understanding and e) a focus on the good qualities that come with autism (Sivberg, 2002). Parents who possess these skills have the potential to become exemplary role models for other parents of a child with autism. Parents and families can be resilient. Masten, (2001) explains that the great revelation of resilience research is its ordinariness. Resilience does not come from rare and special qualities but is drawn from an inner strength.

Parents all need to be confirmed and respected for their efforts in helping their children become as successful as possible. Parents of a child with autism also need this validation, perhaps even more so. These parents are our everyday champions and deserve our utmost admiration and respect.

## Chapter Three

### Research Design and Methodology

#### Purpose

Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem (Creswell, 2002). The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting. The intention of this study was to develop a comprehensive understanding of the experiences of a family affected by autism. A phenomenological design was chosen for this qualitative study. Qualitative researchers not only view the outcome of their research as relevant, but also gain insight into how the process of the phenomenon makes sense to the participant's lives (Merriam, 1998). Phenomenology is an intentional examination of an experience, directed toward obtaining content or meaning from that experience (Mertens, 2005). The rationale for choosing a phenomenological design follows from a need for increased understanding of the phenomenon of resilience in families affected by autism. This study will attempt to draw conclusions about the healthy adaptation of the participants and identify attributes and characteristics they possess that attribute to their apparent strength and durability.

The research questions implemented to provide the framework for the study are:

1. What factors contribute to the resilience experienced by a family affected with autism?
2. In what ways did the family overcome the challenges of autism?
3. How or what can other families learn from the participants?

## Research Design

The data for this phenomenological study will be gathered from a three step interview process (Seidman, 1998) as the process lends itself well to analyzing the parenting and family lifestyle of the chosen participants. Rich descriptive data will be gleaned from the participants for the purpose of drawing insight from them. To generate the findings from these insights or raw data, the qualitative researcher must engage in an active analytic progression throughout the research process (Thorne, 2000). Patton (2002) explains that the researcher must search for meaningful patterns to emerge from the raw data.

Creswell (1998) explains that the phenomenological researcher will examine the meaning of the experiences for the individuals. This study is intended to produce an understanding of the ways in which the participants interact with one another to create a harmonious, coherent family lifestyle which is supportive and fulfilling for each of the individuals, thus defining their resilience. By undertaking a study that embraces phenomenology, a greater in-depth understanding of the every day trials and successes of the participants will be achieved. In relation to the lived experience, interpretive phenomenology goes beyond the essence of the experiences and tries to ascertain what can be learned from the participant's experiences (Lopez & Willis, 2004).

Phenomenology is the study of structures as experienced from the first-person point of view (Bogdan & Biklen, 2003). This phenomenological study is an attempt to better understand the key cultural concepts or the essence of the lived experience of the family members affected by autism. Mertens (2005) explains, "the intent [of phenomenological research] is to understand and describe an event from the point of

view of the participant” (Mertens, 2005, p. 240). The author begins the study with a philosophical ideal and draws upon the existential themes of the participant’s lived experiences (Creswell, 1998).

According to Creswell (1998), phenomenological research translates into an approach that includes entering the field of perception of participants to understand how they experience, live and display the phenomena. Creswell (1998) noted that “whereas a biography reports the life of a single individual, a phenomenological study describes the meaning of the lived experiences for several individuals about the phenomenon” (p. 51).

#### Selection of Participants

Creswell (1998) explains that in phenomenological research there is a narrow range of sampling strategies available due to the necessity of recruiting participants who have the experience of the phenomena. Thus, a purposeful sampling selection process was used to select potential participants for this study. Purposeful sampling is the dominant strategy in qualitative research; it seeks rich information cases, which can be studied in depth (Patton, 1990). Lincoln and Guba (1998) refer to purposeful sampling as choosing participants who are information rich with respect to the phenomenon. The sample group for this study was chosen because the researcher believes that the family demonstrates a healthy adaptation despite the adversity of parenting a child with autism and anticipated that these qualities would emerge through the research. A survey using a larger sample size, for example, could not provide the depth of understanding of the experiences of the participants, which in-depth interviewing can.

## Data Collection

The researcher compiled interview questions that made every effort to determine the characteristics that are accountable for the family's healthy adaptation regardless of the stresses associated with a diagnosis of autism. The first parental interviews took approximately fifteen to twenty minutes and the second, thirty to forty-five minutes. Clarification or a greater understanding of the father's resilience was needed after the first two interviews. A third interview with the father was deemed necessary and was later conducted. The third interview took approximately forty-five minutes. The children were interviewed twice. The first interviews for the children took approximately ten minutes and the second interviews lasted for approximately twenty minutes. The mother was present for all interviews with the children.

The interviews took place in the family's home. After the interviews and prior to the data being included in the final report, the parents were given the opportunity to review the transcript of their own interviews as well as their children's interviews to add, alter, or delete information from the transcripts, see Appendix C. The interviews with the mother and the children were audio-taped and then later transcribed verbatim for analysis at a later date. The father preferred not to be audio-taped and so the researcher complied with his request and wrote notes during his interviews. The father was given the opportunity to review the transcripts of his interviews.

At the end of the interviewing process, the family was provided with a list of support agencies and their contact information. In the event that issues were raised during the process of the interviews that family members would like to seek help with, they would have been directed to access this list of supports, see Appendix F. Family



members were given the opportunity to decline from answering any of the questions that they were not comfortable with and the choice to withdraw from the study for any reason at any time. The decision to withdraw would not have affected the family's access to any services. If a family member chose to withdraw from the study, his/her data would have been deleted from the study and destroyed.

### *Interview Procedure*

The interviews were conducted in the participants' family home. The purpose for this was to gather data as close to the natural phenomena as possible (Creswell, 1998). Seidman (1998) delineates an in-depth, phenomenological process of three interview sessions. This method combines life history (first interview), in-depth interviewing to focus on the assumptions drawn from the phenomenon (second interview), and the final process (third interview) of building upon the foundations from the first two interviews, a time of further reflection, exploration and clarification to participant responses if necessary (Seidman, 1998). Clarification following the first two interviews was needed to expand upon the information obtained from the father and consequently the third interview was conducted with him.

The interviews were conducted after ethical approval for the study was granted from the University of Saskatchewan Behavioural Research Board BEH# 07-151. The mother was interviewed twice and during these times the researcher was able to gather extensive data from her. It was determined that data acquired from the father during the first two interviews was not as comprehensive and, therefore, it was deemed necessary to conduct a third interview with him. The children were interviewed twice in an effort to increase the strength or validity of their responses.

Prior to the interviews, the questions were field tested for validity with the Autism Special Education Coordinator for the Saskatoon Public School Board and colleagues of the researcher. This was done in an effort to decrease the possibility of negative effects during the interview process. During these discussions suggestions for rephrasing some interview questions was made. The consultant and colleagues then concurred with the researcher that the remaining questions were sound and should generate an understanding of the family's experiences.

The interviews were informal meetings that focused on the participant's views and responses to the questions. At least one parent was present at the time of the children's interviews. The interview questions were used to encourage participants to respond in a way that was meaningful and important to them. The researcher facilitated detailed descriptions by using prompts such as: "I know previously you mentioned that you felt validated by the diagnosis but could you go into a bit more detail please". The success of the interviews was due to the established rapport with the family and the comfort level with which the interviews were conducted.

The interviews with the mother and the children were audio-taped. The participants were informed that they could request that the tape recorder be shut off at any point during the interviews. However, the father requested not to be audio-taped at all. The audio-taped responses of the mother and children were then transcribed into written text. Verbatim transcripts were made of each of the audio-taped interviews. The researcher transcribed the father's responses as accurately as possible during the interview process. At the end of each interview, once the written responses were recorded, the researcher discussed the responses with the father to ensure that his true

intents were accurately portrayed in the transcriptions. The parents were given the opportunity to read over their transcripts and the transcripts of their children several times prior to formal analysis. The process of transcribing gave the researcher even more time to reflect on the individual participant's responses and to make meaning of their experiences.

It was important to avoid the risk of making premature judgments and drawing conclusions before all data were collected from the first and second interviews. After the first two interviews were complete it was determined that further data were necessary to represent the father equally. The data collection was inductive rather than deductive method of gathering data. Subsequently, the researcher sought salient details within each interview and also for the relationships among the family participants. Care and precision in the process of transcription was emphasized to encapsulate the lived experiences of the participants. Their true essence was maintained by repeatedly referring back to the participants to ensure that their intended meaning was being presented in the data.

Member checking took place as the participants reviewed their transcriptions. This was the process through which respondents verified their interview data and the interpretations of the researcher (Lincoln & Guba, 1985). It was a fundamental process that affirmed participant responses and validated emerging themes, which enhanced the trustworthiness of the study. It was important throughout the inquiry process that the interview transcripts accurately reflected the information that the participants wanted to convey (Lincoln & Guba, 1985).

## Researcher-Participant Relationship

One key element in conducting useful research is gathering reliable information. Brown (2006) suggests that an interview is a high-quality foundation for assembling information and that the interviewer should design questions that get the kind of information from which the researcher can draw valid conclusions. The purpose of this study was to portray an accurate depiction of the lived experiences of the participants, which was derived from the interview questions. Data were gathered during a series of two and three step interviews with the participants and was then used to determine the strengths and characteristics employed by the family that contribute to their success in raising a child with autism

To facilitate this process, an interviewer must be prepared with the questions and establish a purpose or focus for the interview; however, she must also be flexible because the richness of the data will be obtained in the detailed responses of the participants (Seidman, 1998). According to Ivey and Ivey (1999) the skills necessary for interviewing are: attending behaviors; open ended questioning; observation skills; paraphrasing and summarizing; and helping participants to explore their values and beliefs. The interview questions designed to facilitate this study are attached, see Appendix C.

Rapport between the interviewer and participants is essential. Face-to-face interviews increase the likelihood of the interviewer to establish a connection or rapport with the respondent. The interview process allows the interviewer to observe as well as listen and permits more complex questions to be asked than in other types of data

collection (Gall, Gall & Borg, 2007). Building the interview relationship theoretically begins the moment the potential participants hear of the project (Seidman, 1998).

## Data Analysis

Analysis is an explicit step in conceptually interpreting the data set as a whole, using specific analytic strategies to transform the raw data into a new and coherent depiction (Thorne, 2000). The steps to analyzing phenomenological research according to Cohen and Daniels (2001) are: a) the researcher must immerse herself in the data which requires reading the transcripts several times b) the statements or units of meaning that are relevant to the phenomenon are then identified and coded from the raw data and categorized c) these excerpts become refined into the themes and are then used to develop a thorough description of the participant's experience of the phenomenon (p. 4). This description is often referred to as situated structural description (Cohen & Daniels, 2001).

Analysis of the content was explored to discover the nature and implications of the experiences of the participants. The researcher then absorbed and assessed the data, which required reading the transcripts several times to discover an emphasis on commonality and emerging themes (Patton, 2000). After initial overviews, the transcripts were read numerous times to ascertain salient details from the participant's responses. Essential components surfaced from the raw data during these readings and the significant units of meaning became apparent. The researcher scrutinized the data and identified the broader units of meaning by using a coding system to identify commonalities among participants. Each participant's transcripts were highlighted with a colour coding system of marking the excerpts in the text to quickly identify these

commonalities. Examples of the units of meaning that were coded and grouped include: adaptation, children's confidence, hopes, dreams and commitment.

The categories were then narrowed down from these units of meaning (Patton, 2000). Upon repeated and close examination of the coded data, the researcher developed the categorizing system. Categorizing involves organizing coded data units into groups identified through similar characteristics among participants (Lincoln & Guba, 1985). According to Lincoln and Guba (1985), the essential task of categorizing is to bring together categories that relate to the same content. Some of the categories created were grief, flexibility, support, skills and attributes.

These general categories evolved into the developing themes. The final themes used for analysis were: a) adversity and stress b) acceptance and understanding c) adaptability and flexibility d) self-efficacy e) strength and determination f) support from family and friends. These themes were consistent among the responses of the parents and were used to develop an exhaustive description of their experiences of the phenomenon (Bryman & Burgess, Eds). This systematic procedure of identifying relationships or themes in the data is referred to as phenomenological reduction (Thorne, 2000).

The children are young and therefore the data collected from them is limited. However, without the data gathered from the children during their interviews, there would not have been a composite depiction of the family unit. Although worthy of inclusion, it is hard to extrapolate their data into the themes consistent with the parents. Due to their ages, their interview responses are not as articulate or as detailed as the data collected from the parents. However, they offer a clear indication of their resilience in

the responses they do share. The resilience apparent in the children is demonstrated in the themes of self-efficacy, strength and determination, and support from others.

Data were analyzed to isolate any variance among participants. The themes were compared among participants to identify commonalities and shared themes. By using these steps large quantities of data was reduced to the essential elements of the individualized experiences of each participant (Thorne, 2000). Data was broken down into manageable parts, synthesized, and searched for patterns to discover what was important and what could be learned (Bogdan & Biklen, 2003). The researcher examined the data for certain words, phrases, ways of thinking, or patterns of behaviour that could be identified as a unit of meaning.

An emphasis on commonality among the parents' transcripts, and to some extent the children's, was sought to verify the consistency in the emerging themes (Lincoln & Guba, 1985). See figure 1, page 48 for an illustration of six evolving themes. A comprehensive description of the phenomenon was developed from the transcripts of the participants to ensure the researcher encapsulated the essence of their experiences (Moustakas, 1994).

Once data from all interviews was compiled and analyzed, a composite description of the phenomenon experienced by all four participants was evident. Excerpts from the transcripts of both parents appeared in all of the units of meaning and subsequent categories and themes. The data from the children was less comprehensive but was included in all but one of the final themes. As the data were collected and analyzed, the interpretative framework was constructed. New themes stopped emerging

after the final interview with father and the researcher determined that data saturation had occurred.

Analytic or data saturation occurs in phenomenological research when no new information or themes are observed (Patton, 2002). Member checking throughout the analysis process occurred. The researcher frequently contacted the parent participants through phone discussions and e-mail correspondence to increase the validity of the findings. The researcher confirmed with the participants that the analysis of the emerging categories and themes were true interpretations of their intended meanings. The data collection process was then terminated.

Credibility checks were used to ensure validity through consulting with the participants throughout this process. Formal analysis of the data followed once the member checking was complete and the signed transcriptions from the interviews with the parents and the transcriptions from the children's interviews were obtained. The objective of the current study was to achieve transcendental subjectivity, which was accomplished by constantly assessing biases and preconceptions through reflection by the researcher (Lopaz & Willis, 2004). The messages drawn from the data needed to reflect the unique meaning of each participants' experiences.

Upon analyzing the transcriptions, questions regarding the father's data arose and clarification was needed. It was deemed necessary to conduct a third interview with the father. Interview questions were formulated and the researcher consulted with colleagues regarding their efficacy.

The process of analysis was an evolution of the research design itself. Creswell (1998) delineates the following process for analysis of phenomenological research:



- a) The researcher begins with a full description of the participant's experience of the phenomenon derived from the interviews.
- b) She then finds statements in the interviews about how the participants are experiencing the phenomenon and works to develop emerging themes.
- c) Statements in the transcripts are then grouped into units of meaning.
- d) The researcher then seeks to find all possible meanings, commonalities and divergent perspectives.
- e) The researcher then constructs an overall description of the essence of the experience of the participants.
- f) This process is followed for the researcher's account and then for that of each of the participants in the study (p. 147-150).

The phenomenologist does not view the human experience as invalid but rather as a cornerstone of knowledge about the phenomenon (Cohen & Daniels, 2001). The experiences described by the family members contributed in the understanding of the phenomenon of resilience in a family affected by autism and gave significance and meaning to the study. Lincoln and Guba (1985) recognize the characteristics that make researchers the instrument of choice for naturalistic inquiry: people are responsive to environmental signals, and are able to interact within the situation to form an insightful analysis.

### *Representing the Data*

Originally, the data from the mother seemed to overshadow the information from the other participants. It was necessary to reassess the input from the father. The third

interview from the father created a more extensive depiction of all of the participants' contributions to the study. Once the analysis from all interviews was complete the data were grouped into an equally weighted summary for each parent. The data collected from each parent were considered with equal value; however, the quality of data from the children is significantly limited by their ages. Moustakas (1994) refers to this balancing process as horizontalization, the second step in phenomenological data analysis in which the researcher creates an equal value inventory of all the major accounts that are relevant to the research topic.

Each participant and his/her account was clarified and presented in context to give the reader a complete picture of the family's emerging resilience. The researcher created an ideology as the information from the transcripts emerged (Seidman, 1998). In this way the researcher and participants collaborated together to generate an understanding of the phenomenon. Seidman (1998) substantiates the essence of interviewing in the following statement:

We interview in order to come to know the experience of the participants through their stories. We learn from hearing and studying what the participants say. Although the interviewer can never be absent from the process, by creating a profile in the participant's own words, the interviewer allows those words to reflect the person's consciousness. (p. 102)

The researcher created an ideology as the information from the interviews emerged (Seidman, 1998). In this way the researcher and participants collaborated together to generate understanding.

The researcher does not assume or suggest that any of the processes outlined in this study can be generalized to the circumstances of any other situations. Caution on behalf of the reader should not be taken to generalize the circumstances of this particular

family and the findings derived from their interviews. The reader should recognize that the information is context-bound and unique to this particular family. This study should simply illustrate coping strategies that have been successful for this specific family.

### *Researcher Interpretation*

The researcher's interpretation of the data is complex (Gall, Gall & Borg, 2007). In order to interpret data in a systematic, purposeful and appropriate method of investigation, the researcher needs to utilize existing knowledge. Dey (1993) explains that the issue for the researcher is not whether to use existing knowledge, but how to use it, stating that: "the danger lies not in having assumptions but in not being aware of them" (Dey, 1993, p. 63-4). The view that the researcher acknowledges active participation between researcher and participants has replaced the view of the researcher as a value-free and objective observer (Wheatley, 1992).

The researcher balanced the potential benefits of researcher involvement with a commitment to accurately represent the voices of the participants. Massey (nd.) explains that experiencing the world subjectively is a way of life and is therefore an inevitable aspect of the research process. A balance must be created between refraining from bias and using one's present understandings and beliefs to inquire intelligently (Massey, nd.). The teaching experiences of the researcher did not purposely bias the results but rather set the groundwork for the study.

### Trustworthiness

To trust is to have confidence in someone. The Oxford English Dictionary (2002) defines trustworthy as "honest, truthful, and reliable" (p. 901). The contact between the

data collector and the participants is intrinsic to qualitative research and relies deeply on trust (Kvale, 1996). Patton (2002) states that the interviewer is the instrument and her role is to recognize the connections and relationships and to minimize the misrepresentation that can occur during the interview process. It is upon this basis that trust was formed. The participants have a sense of confidence with the interviewer and the researcher must trust the information from the participants. Atkinson (1998) suggests that a good interviewer should strive to develop trust and mutual respect with the participants and cultivate a relatively neutral role but be compassionate and considerate towards the participants.

Qualitative research is a method that examines contemporary real-life situations and provides the basis for the application of ideas and extension of methods (Patton, 2002). Etherington (2004) recognizes that the bond between the participant and the researcher is not only valuable but also essential. It is an attempt to make the unfamiliar familiar. It is through this intense revealing process that qualitative research exposes the participants through a relationship built on mutual trust and respect (Patton, 2002).

## Summary

This study involves only one family affected by autism and is limited in that respect. The circumstances of this particular family and the findings derived from their interviews are context-bound and unique to this particular family. It is important to note that a preconceived perception of the family's healthy adaptation in spite of the adversity of parenting a child with autism was the foundation that led to this research topic. The relationship established between the interviewer and each of the participants determined the intensity with which the salient facts were imparted to the researcher.

## Chapter Four

### Results

#### Overview of Results

This chapter examines the impact of having a child with autism in the family unit. Below are the research findings derived through an interview process with all members of a family affected by autism. The purpose of the interviews was to discover the everyday lived world of the participants, which was followed by the researcher's data analysis or exploration of their experiences. The unstructured, open-ended questions allowed the respondents to answer from a variety of dimensions based on their unique experiences. The focus of the interviews was to draw insight for the research questions:

1. What factors contribute to the resilience experienced by a family affected by autism?
2. In what ways did the family overcome the challenges of autism?
3. How or what can other families learn from this family?

Phenomenology is essentially the study of the experiences of the participants (van Manen, 1997). Its emphasis is on the world of the participants and how they live it. Shank (2002) explains that the successful qualitative research has the ability to observe, converse, and interpret the data. The inquiry process into the experiences of the participants unfolded as the researcher conversed with the participants, then observed the recurring units of meaning consistent among their transcripts and finally, interpreted the data.

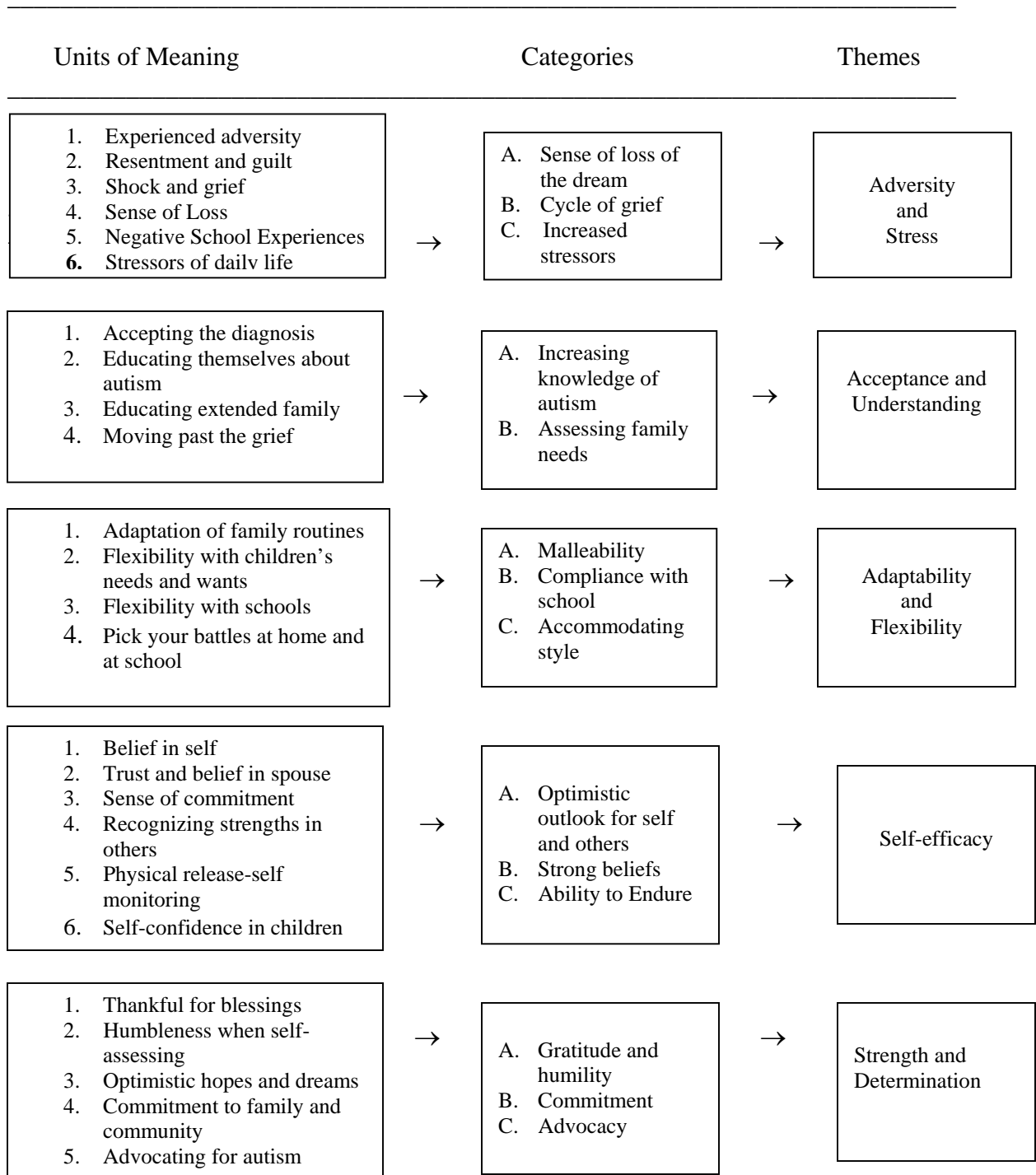
The categories in figure one were derived from the initial units of meaning. Transcript selections were combined due to similarities and commonalities among the

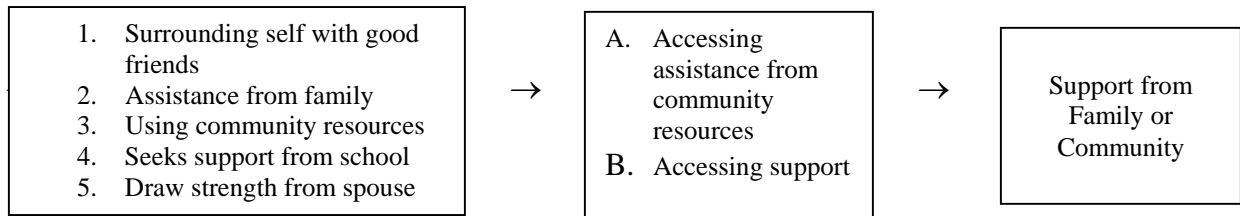
parent responses and to some extent the children to form the general categories. The children were not represented in all units of meaning, categories and themes. For example, they undoubtedly do experience stress and negative experiences due to autism but they did not articulate this during their interviews and therefore their input is not reflected in the theme of *Adversity and Stress*.

Further analysis of the data to discover relevant information then refined the categories and the six themes evolved. In all six sections of the units of meaning there were consistencies between both parents. For example, excerpts from the transcripts of both parents articulated ways in which they surround themselves with friends, seek support from school, access resources, gather assistance from family, and draw strength from one another. The children both expressed ways in which they feel supported and validated by their parents but did not offer dialogue to fit into each of the five points in this unit of meaning. The commonalities among all participants' transcripts were colour coded and then collated in the sixth category of A) Accessing assistance from community and B) Accessing support. This category was then further analyzed and developed to incorporate the unified data of all participants. This category was then refined into the final theme of *Support from Family or Community* to assist the researcher in summarizing the salient details of the participants.

It is necessary to clarify that the factors that promote the participants' resilience, such as their intact family unit, and the characteristics of people with resilience, such as the ability to effectively problem solve, are interconnected. For example, it is difficult to determine if the parents sought assistance from their community because they possess the characteristics of strength and determination or if the process of community assistance

facilitated their strength and determination. It is important to note that the final six themes do not occur in isolation but rather are interrelated to form the complete representation of the participants' resilience. See Figure 1 for an illustrated account of the evolving themes.





*Figure 1.* Emergence of Themes

Initial units of meaning and active categories and themes emerged from the raw data as the researcher listened to the audiotapes several times before, during and after the process of transcribing. The researcher then read the transcriptions on numerous occasions and identified potential patterns among the participants. Patton (2002) explains that the researcher must uncover the emerging patterns by carefully analyzing the transcriptions. Allen (1995) stressed the importance of thoroughly reading and developing units of meaning from data as central to the production of the phenomenological strategy. The production of meaning occurred through this reflective process of reading and drawing interpretations from the raw data.

It was during this progression that significant statements were extracted from the transcripts by the researcher. Units of meaning were extracted and formulated for the purpose of analysis. Categories evolved from the extracted transcript dialogue and the themes unfolded. The excerpts were coded for each section of the transcripts with titles that described the attribute or characteristic that emerged. Koch (1996) explains that a pre-understanding of the subject area and the interpretive framework of the research can be bridged to create a perception of the participant's experiences. The categories evolved from these larger units of meaning and were then refined into themes.



The information generated from the first two interviews with the mother was significant and extensive. Upon analysis of the father's first two interview transcripts it became apparent that a third interview would be necessary to clarify certain points and to give the father's experiences equal worth. Necessary revisions were made and the new information was integrated to create a more complete portrayal of both parents. After the interviews were complete, a synthesis of all meaningful units was constructed into categories, which then advanced into the final themes. Analysis of the data from the parent's interviews ultimately resulted in the identification of six themes: adversity and stress; acceptance and understanding; adaptability and flexibility; self-efficacy; strength and determination; and support from family or community.

The children are both young and consequently their ability to coherently portray their resilience is limited in that respect. As well, due to his autism, the son had some difficulty communicating his thoughts during the interviews. Therefore, the data collected from the children does not appear in all of the themes.

The goal of analysis in phenomenological research is to develop the participant's experiences into a story that depicts the main themes of his/her journey. This chapter imparts the narratives from participants incorporated with reflections of the researcher on their experiences. The following is their story.

#### Introduction of Participants

Participants have a right to be protected against the vulnerability; which can occur as a consequence to sharing personal qualities of their lives (Gall, Gall & Borg, 2006). The participants have been given pseudonyms for this study and small particulars have been changed to provide further anonymity. The participants were enthusiastic about

sharing their lived experiences for the purpose of this phenomenological study and the candor and honesty with which they told the stories of their experiences provides a richness that would not have been possible without their outstanding contributions.

Brayden is an eight-year-old grade three boy with autism. Brayden attended the Integrated Preschool where the researcher taught as the special education program teacher. The Integrated Preschool is a program that combines six children with various special needs designations with nine typical or neighbourhood children in each of a morning and afternoon program. Brayden was officially diagnosed with autism at the age of three and was therefore eligible to participate in the program as one of the designated children. Brayden has a high functioning form of autism. He has expressive and receptive speech and functions well in an inclusive classroom with the assistance of an educational assistant.

Paige is Brayden's younger sister. She is six years old and attends the same school as Brayden. The researcher had the opportunity to teach Paige in the Integrated Preschool Program as one of the typically developing children in the program. Paige is a delightful young girl who was an exceptional social and language model for the designated children in the classroom.

Brigit is the mother of Brayden and Paige. By having the opportunity to observe Brigit through the past several years, the researcher has made several observations of the outstanding parenting characteristics that she exhibits. The researcher believes Brigit is an exemplary model for parenting a child with autism. The researcher deems her to be the pillar in this family upon whom all the members depend upon and it is her perseverance and dedication that inspired the researcher to conduct this in-depth

phenomenological study to try to discover which attributes contribute to their family's success. The interviews with Brigit were very extensive and offered valued information and insight into the lives of the participants.

Ross is the father of Brayden and Paige. Because Brigit is the parent who has transported the children to and from school and has attended parent/teacher conferences and personal program planning meetings, the researcher has come to know her in a greater capacity than Ross. However, the dynamics of their family life would not be completely represented without the father's perception and input. Through the interview process, a better understanding of Ross's role in their family routines was discovered.

#### Presentation of Themes

In this chapter the data analysis of in-depth personal interviews with the family of participants is conveyed. The categories, units of meaning and themes emerged from the data and will be investigated and discussed in this chapter to convey the meaning of the lived experiences of the participants. The data analysis of the parents' interviews revealed six themes: adversity and stress, acceptance and understanding, adaptability and flexibility, self-efficacy, strength and determination, support from family and friends. All of the theme groupings contain a representation of both parents. The children's account or lived experiences are not represented in the theme of adversity and stress but are included in the succeeding themes. The lived experiences of the parents, as revealed through the interviews, represents the greater part of the data analysis. The inclusion of the children's data serves to enhance the responses of the two primary participants, Brigit and Ross. The subsequent sections of this chapter are the presentation of the emerging themes developed by the participants.

During the interviews prominent details that arose from questions such as: “When and why did you first suspect that your child was not developing typically?” and “How did you respond or react when you first heard the diagnosis of autism?” identified the following units of meaning: shock, resentment, guilt, the overwhelming sense of loss, and the daily stressors involved with parenting a child with autism. The parent participants expressed a common sense of loss of their dreams for their child. These emotions and the details about their cycle of grief became one category within the transcripts, which was then included in the theme of adversity and stress associated with the autism.

### *Adversity and Stress*

Although this is a study of strength and resilience, one cannot be perceived as resilient until first faced with adversity. Resilience refers to the process of overcoming the negative effects of risk exposure, coping successfully with trauma and the avoidance of negative outcome associated with the risks (Luthar, 2003). The typical expected outcome of parents of a child with autism would be to struggle with anger and guilt when considering the delayed development of their child (Rutter, 1978). Bromley, Hare, Davison and Emerson (2004) explain that parents of children with autism are more likely to experience serious psychological distress than parents of children with other developmental disabilities because autism is a complex and difficult disability to understand. Brigit illustrates the stress and resulting emotions of having a child with special needs:

*I worry about things that probably other parents don't worry about as much. If the day has gone badly I become more preoccupied with how I do things. I hope that I can do better the next day and I worry that I should do things better. I think if I had controlled things better, then the children wouldn't fight and my daughter wouldn't get hurt. There is guilt involved. There is a lot of guilt that each mother*

*has but it's more so if you have a child with special needs. The thoughts you have are a little more intense than for other parents. It is also painful to watch him struggle. Sometimes it is physically painful to interact with him if he is having a melt down and is attacking me or hurting me with his words or with his hands. I know that these are things that other people just aren't dealing with (Brigit).*

When first learning of the diagnosis there was a sense of loss or grief. Bowman (1997) portrays this manifestation of grief as “a loss of dreams is more than change or even disappointment: it describes the loss of something for which there has been, and is, a significant amount of emotional investment - losses we did not anticipate” (p. 76).

Upon first hearing of his son's diagnosis, Ross' reaction was one of grief, disappointment, disbelief and also resentment. He describes the initial emotions related to Brayden's autism:

*I felt a sense of loss from the heartache around Brayden not having what most would call a normal life. In the beginning, we assumed the worst with him as our understanding of the condition was not as sophisticated as it is now. We see considerable growth and development with Brayden now, and we have come to terms with his condition. That being said, there are times when I look at other children and wish things were more traditional. I feel frustrated when I think Brayden has understood what I expect from him, just to have him turn around in the next minute and do the opposite. His unpredictable behavior is sometimes a challenge. I expect that as he ages, he will mature and be able to handle more responsibility. I also have felt resentment towards the autism, in general, because it dictates so much of our lives (Ross).*

This reaction illustrates that Ross' experience of learning the diagnosis of his son was unpredictable and brought unimaginable heartache. The grief cycle is a natural process when one experiences a loss and when Ross and Brigit received the diagnosis of autism they went through this cycle due to the loss of the hopes and dreams that they had for their child (Naseef, 2006). With reference to the early days prior to formal diagnosis the participants state this:

*It is frustrating to see your child be frustrated. It hurts your heart and you just want your child to be happy. No one wants his or her child to be uncomfortable or unhappy (Brigit).*

*With other disorders you can warn or predict what their behaviour is going to be like. With a spectrum disorder like autism there is no telling from day-to-day or child-to-child what it is going to manifest itself like. Experts cannot entirely explain what treatment is best or what your child's life is going to be like so I was frustrated for many years (Ross).*

When a child has autism, the unexpected and permanent nature of such a disorder increases a parent's vulnerability to stressors (Quill, 2000). Brigit and Ross experienced adversity and stress associated with their son's autism. The parents expressed feelings of self-doubt and trepidation. Brigit recalls a time of fatigue and depression:

*There were times that I felt overwhelmed. I felt sad for my son because I didn't understand, as much as I had read about it, I didn't know what impact it would have on his life. There was no way for anyone to tell me or predict what his life was going to be like. I can remember being discouraged (Brigit).*

The parents were not void of the negative impacts due to autism; however, they were able to prevail and overcome their many challenges. Ross and Brigit clarified that although the diagnosis seemed at first tragic and overwhelming, they had the fortitude to do what was needed to improve the life of their son. Their first step in recovering from their grief was acceptance and understanding.

In response to questions such as "How does your child's diagnosis affect your family life, and how do you cope with these challenges?" and "If you could talk to other parents with a child with autism, what suggestions would you have for them?" evoked statements regarding their acceptance of Brayden's autism, the need for information about autism for themselves, their daughter and for the purpose of educating their extended families. Salient details about how they rallied into action and moved forward from the grief were also outlined. Consistent statements from both Brigit and Ross about

accepting Brayden's autism, the need to educate themselves about autism, and the ways in which they were able to move past the grief became the units of meaning for the following theme. These selections were then assembled into the category of increasing knowledge and assessing the needs of the whole family. The information in this category was then enhanced into the theme of acceptance and understanding.

### *Acceptance and Understanding*

During the interviews the parents made several references to their personal journey of understanding and acceptance. Brigit had suspected early on in Brayden's young life that he was not developing typically. She had a friend with a child the same age as Brayden and so noted that his development was not typical.

*Everyone around me just said that Brayden was a content and happy baby, and that I should just thank my lucky stars and not think about it too much.....but I would watch him, and although you are not supposed to compare children, I thought there is something different. My friend's son babbled, he expressed himself differently and he certainly showed a full range of emotions that my son did not show (Brigit).*

Brigit and Ross experienced a sense of relief with having knowledge about autism. Once they had the diagnosis they could better understand Brayden's behaviour and could also plan for the future. When she first heard the formal diagnosis from a team of professionals at the Kinsmen Children's Center, she recalls feeling, among other things, validated:

*Some people might have felt that the world had crashed in. I just had a word now for what I already knew was my child. I walked out with the same child that I walked in with. The diagnosis didn't change anything; it just gave me power to get help for my son. I was relieved to have the word but at the same time I felt sad for my son. All I knew was that he was going to have this life long disorder (Brigit).*

Brigit's reference to the diagnosis as power is a key factor in her resilience, as the ability to advocate for their son will facilitate their family in achieving protective factors such as support and services from agencies. Ultimately, she understood the Brayden's autism did not alter her love or devotion for her son it empowered her.

Ross recalls that he did not come to accept the diagnosis as readily as his wife but during his second interview he clearly demonstrates his acceptance by what he has learned since the early diagnosis. Ross states his thoughts on acceptance:

*Acceptance starts with understanding.....the diagnosis is a gift, it gives you the right to demand teacher assistants or other appropriate treatment in schools and it gives you a context to do your own research to better understand the disability. You love your child, having a label provides you with the ammunition to fight for your child (Ross).*

Due to his autism, Brayden has difficulty answering questions and so his ability to articulate or demonstrate resilience is limited in that respect. During Brayden's second interview, he was asked what he would tell a famous person about autism. He displays the acceptance of Brayden's autism with the ease in which he replied to the question:

*I have autism. It is a thing of yourself. Autism is your special ability; it is autistic. I have autism so I think people should treat me nice (Brayden).*

Marcus, Kunce and Schopler (1997) explain that siblings of children with autism learn about stress and family pressure early on and tend to mature quickly. Harris and Glasberg (2003) clarify that some siblings of children with autism are more vulnerable to worrying, anxiety, anger and depression. However, some siblings may also develop a higher level of warmth, empathy and responsibility than their age alike peers if these skills are modeled by their parents (Harris & Glasberg, 2003). Brayden's sister Paige is six years old but when asked how all children should be treated, even if they are different, she responded with this statement:



*We have to be friends with everyone at school, even if they are different, you do the same things. Like if someone talked different you might not understand them but still play with them. If someone had legs that didn't work we would just play games that she could play. We have to play nicely together (Paige).*

Paige exhibits an exceptional understanding and acceptance towards children with disabilities. She undoubtedly comprehends that all children, despite differences, have equality and a right to be treated with respect. She demonstrates this within the context of her statement.

Acceptance is difficult to articulate but once experienced, the parents understood its effectiveness and why it is a necessary progression after hearing the diagnosis. Ross and Brigit reveal the acceptance of their son's autism in their responses to the questions and also in how they live their lives. A statement from Ross' interview is included:

*This is just what you do when you have a child with autism. Brayden has always had autism and our family dynamics have evolved in that each and every one of us has had to adjust to make it work. It has been an evolutionary process. (Ross).*

Ross and Brigit understand that there is no right or wrong way to deal with the many challenges they face and take pride in their job of parenting their children. The acceptance, understanding and love for their children have led them to the next stretch of their journey to resilience: adaptability and flexibility.

Significant data for the following theme was derived from the questions: "What school modifications and accommodations have been necessary for your child?" and "Please list some examples of the steps you and your family have taken to ensure your success in parenting a child with autism." Ross, Brigit and Paige all illustrate ways in which they skillfully make modifications in their lives. Adaptation for family routines, flexibility with Brayden's needs, necessary alterations at the school level and the ability to be flexible became consistent units of meaning in the transcripts. The category of

malleability, compliance and accommodation unfolded and then was developed into the theme of adaptability and flexibility.

### *Adaptability and Flexibility*

Adaptability and flexibility are crucial characteristics of a family that is affected by autism. O'Brien (2007) is of the same opinion and attributes resilience in families affected by autism to flexibility. It was important for Ross and Brigit to identify the elements that enabled them to cope effectively and emerge from crisis or distress with strength and fortitude. Brigit and Ross were able to withstand adversity of these stressors and rebound successfully because of their skills in adaptability and flexibility.

Brigit remembers that because experts could not ultimately explain what treatment is best or what her child's life was going to be like, she was frustrated for many years but had to learn to adapt. She demonstrates the necessity of developing flexibility and that learning to become accustomed to Brayden's needs was complementary to their adjustment after the diagnosis of autism:

*I am a type-A personality and I want to know things. I wanted to know everything that I could about autism. There was no way for anyone to tell me or predict what life was going to be like. When you have a child with Down's syndrome or cerebral palsy, these diagnoses have some kind of patterns and similarities. With autism you don't but I wanted to plan. I had to let go of a lot of thoughts about what I wanted and what I wanted for my child. I had to let my son dictate how our lives were going to be... I think that was the biggest thing, I had to let go of that need to control or micromanage every aspect of our lives and just learn to go with the flow a lot of the time (Brigit).*

The behavioural needs of the child with autism are complex and can often cause disruption in the family's daily routines. The presence of a child with autism escalates life stresses in magnitude, intensity, duration, and unpredictability (Marcus, Kuncze &

Schopler, 1997). With reference to the adaptations of daily life experiences this family expressively illustrates their adaptive dimensions. Ross describes the adaptations needed during a recent trip:

*We recently went on a trip. We required considerable time to discuss the trip with Brayden to prepare him so that he understood what was going to be happening at all times. He is very punctual and watches the time very closely. So we used that to our advantage. It was comforting for him to know what time we would be arriving at the airport, what would happen as we went through security, how long the flight was, where he was going to be seated, etc. We knew that the more detail we could provide, the better the flight would be. Once there, finding common things that reminded him of his routines at home was important. This allowed him to adjust properly. The flight home was easier as he had an idea in his head, so he knew what to expect. The less surprises for Brayden the better (Ross).*

Consistency is the core element of healthy emotional development for all children but a child with autism requires an even greater consistency in their physical world (Quill, 2000). Ross and Brigit describe some of the typical daily routines and how they adapted to accommodate Brayden's needs:

*As a parent you want to do things efficiently and you battle the need to control. When getting ready for school in the morning, I try to give up doing things for him that he can do for himself. It could go quicker if I just assisted him with dressing. I've had to modify my morning routine to allow him to do things for himself. I have to allow time for him to do his routines and when I am rushed in the mornings it can be a frustrating task (Brigit).*

*Transitioning aspects sometimes create challenges for us but modifications that facilitate a smoother transition are...structure, routine and more structure. We make his life experiences as consistent as possible (Ross).*

A major decision or adaptation that Ross and Brigit have made together is that Brigit will stay at home with the children. In this way she is able to provide consistency and harmony for their family unit. Brigit describes her commitment to their family:

*I knew that I wanted to do a good job as a Mom. I made a conscious decision to stay home with my kids. Some people may feel constrained by giving up or sacrificing a career but those things were not a problem for me...I don't know*

*how I would manage both a career and my home life, at least right now. My husband and I have taken steps to secure all of our needs now and in the future (Brigit).*

This family has risen to the challenges they face due to autism and responded with strength and courage. Their enhanced coping strategies have been advantageous to them. Ross and Brigit resolved some of their challenges of stability and routine with their decision for Brigit to stay at home. In this light, Ross states his perspective:

*With Brayden, consistency and routine are important. We have decided that the single most important thing we can do for Brayden in his development is to keep his Mom in the home. With my work, my hours are erratic and chaotic. It is important for Brigit to be available for the children at all times (Ross).*

Early intervention programming and educational experiences are crucial for children with autism (Quill, 2000). Quill (2000) explains that it is necessary to repeatedly teach children with autism to filter out distractions, to feel comfortable in the school setting and distinguish relevant information. Ross and Brigit enrolled Brayden in early intervention programs by the age of three and continue to sustain good relationships with his educators. Neither the classroom teacher, nor parents alone, can meet the diverse needs of the child with autism. There is a need for a collaborative effort to successfully meet the child's needs. With regards to Brayden's educational experiences, these parents demonstrate an adaptability to advocate for their child. They offer their personal view of the inclusive classroom:

*The inclusive classroom is excellent. I believe it teaches Brayden appropriate behaviour to situations and teaches him appropriate social interaction skills. On the down side, some of his past teachers have been reticent to tell his peers that Brayden has autism. This has alienated him somewhat in the classroom. By not telling his peers that he has autism, they don't all understand his behaviour when he acts out and it leads to alienation by some children. However, inclusion has been mostly positive for him, Brayden wants to be with other kids and play with them. I think it is important for the teaching staff to identify good partners for him. Peers who are good role models for behaviour, which they want to stress*

*with Brayden, are the best choice. As far as his classroom behaviour, we have seen great improvements. The teachers make efforts to ensure that he is interacting on the playground as well. He has also found his own friends. We are very fortunate that he found a group of boys who like the same activities and are able to interact positively with him (Ross).*

Ross articulates the benefits of children with special needs learning from their age alike peers. Children with autism need considerably more time to learn the social skills needed for a school setting (Weiss & Harris, 2001). Not every peer will have the benefit of being a good role model; however, by partnering Brayden with good behaviour role models, he has been able to have a positive inclusion experience. Ross and Brigit work collectively with the school to ensure that Brayden gets the intensity of instruction needed and is able to build the necessary social skills to make his experience constructive.

*I think ideally, an inclusive classroom is a wonderful idea if it is done right. That being said, it depends on the teacher. It depends on the attitudes of the other parents, and how other children are allowed to interact with one another. I respect the decisions of his teachers. I feel that when you have a special needs child and you are putting him in the regular class, you feel a sense of gratitude even though you know that he has every right to be there, you do know that there are extra modifications necessary from the school. For example, at first my son needed to be seated in the same place all year but now he has adapted and is able to be relocated. Teachers also have to be cautious about who they partner him with. They are very careful of who they chose. There is an effort from the teacher involved to make things go right, but if the teacher is a good person and does try to adapt things you feel a sense of gratitude for what you have. You may not agree with everything but if you're smart, you'll pick your battles (Brigit).*

Brigit and Ross appreciate that the most effective environment for Brayden's education is one that combines a creative, supportive teacher and cooperative, informed peers. Making a smooth transition to the inclusive classroom involves collaboration between school and home (Weiss & Harris, 2001). When Brayden was younger Brigit was able to adapt her schedule to assist staff with behaviour concerns and necessary

interventions for her son. Ross and Brigit have succeeded in working together with teachers, educational assistants, administrators and special education personnel. Their malleability when working with these teams has enabled Brayden to be successful in the school setting. They are understanding and respectful of the stress involved with his education and strive to have good communication between school and home.

Ross and Brigit have also worked towards educating their daughter about the specific needs of children with autism. Paige demonstrates her understanding that Brayden requires special considerations at school:

*At school Brayden gets more attention because, well, he is autistic. That means you are different from other kids (Paige).*

Assisting children with autism in the school environment requires flexibility. This can be a formidable task but Brigit and Ross have been instrumental facilitators and with careful planning, clarification of roles and adaptability of all supporting members of the team, Brayden's experience has been a valuable experience. Consistency for expectations between home and school has been crucial for Brayden. Ross and Brigit understand that it is important to maximize the similarities within the two settings to minimize the distress of their son.

Children with autism function well with similar routines and changes to these routines can be stressful events. Strategies that have been successful for easing the transitions for their son are having extensive conversations with him in advance of changes and the use of Picture Exchange Communication System (PECS). PECS was developed as a procedure to augment spontaneous communication in nonverbal children with autism (Quill, 2000). When Brayden was younger the family depended mainly upon

PECS to illustrate transitions, necessary routines, and possible changes to their schedules.

Brigit explains her past and present strategies for easing transitions:

*More often than not I am aware of when change is going to happen ahead of time so I will have many conversations with him to prepare. We don't have to use PECS as often now. I used to have to use them or draw a picture to try and illustrate a change in schedules or if there was going to be a change in teacher or his routine but now we can discuss these changes. We have very long bedtime conversations (Brigit).*

Ross and Brigit clarify that life with their son is in a constant state of flux.

Change is inevitable in life and uncontrollable events occasionally dictate altered routines but Ross and Brigit prepare for this. Ross suggests this strategy to accommodate a sense of equilibrium for their family during altered times:

*Being mentally prepared for changes includes accepting that when change is inevitable there will likely be repercussions. For example there may be more sleepless nights in the beginning of a new school year. You know things are going to be rough so it's not a surprise, you prepare for it (Ross).*

Sivberg (2002) suggests that parents of children with autism need to be efficient and that without functional and flexible coping strategies, they run the risk of burn out effects.

For Ross and Brigit, knowing and accepting that things may sometimes be unpredictable helps to alleviate some of their stress.

An example of their problem solving ability is apparent in the way they accessed the public paddling pools in summer. When it came time to leave the pool, Brayden would have tantrums or physical outbursts that included yelling, crying and hitting. Consequently, after the initial unsuccessful departure, the parents made some alterations to the experience. They decided to arrive at the pool one hour before it closed down for the day and in this way Brayden could physically see that the water was being drained from the pool and could then understand that their swimming time was finished.

Brayden has very specific patterns or routines that he needs to follow in the morning while getting ready to leave for school. A part of his routine includes the need to be the first person to leave the house each day. Typical siblings would likely be unaffected by the order of departure but for Brayden this is significant. If he were not allowed to be the first person to leave it would likely result in a physical outburst. Paige is able to understand that accommodations to life's simple routines are required in their family. Paige straightforwardly explains one way in which she helps to alleviate the stress of this morning routine:

*Autism means you are different from other kids. When we go out of the house, we always let Brayden go first because he is autistic. He needs to go first (Paige).*

Ross and Brigit recommend that structure and predictability at home during times of unavoidable changes can reduce the stress for the whole family when unpreventable circumstances occur. Transitions into a new school year, holiday plans or visits to the doctor are times when they need to diligently maintain their typically scheduled agenda at home. These are times when they work together as a team. Ross describes a past stressful time in their lives:

*I refer back to when my wife's mother was ill and needed her almost as much as the children. I was able to recognize how much stress was on her shoulders, and stepped up. I was able to see how much time and energy she uses raising the kids, especially with a child with special needs. I was able to assist with maintaining the necessary routines for the children and I think it made me more empathetic to her daily routines (Ross).*

Sivberg, (2002) concurs that a strong sense of cohesion assists parents to cope better with their daily tasks in parenting a child with autism. The family of participants has learned to adapt readily and their resilience comes from their malleable qualities and ability to learn to live with the occasional uncertainty. Through their interviews, Ross



and Brigit demonstrate these qualities of resilience. Brigit and Ross' resilience was obtained gradually. Resilience is acquired progressively step-by-step and then internalized by the individual (Alvord & Grados, 2005). Ross and Brigit steadily developed their resilience as they educated themselves and learned new strategies to create a cohesive family unit. This enabled them to adapt to life's difficult situations as they arose.

Self-efficacy is a means to their resilience. Maintaining a belief in their own abilities was the next unit of meaning that emerged from the transcripts. Units of meaning such as: recognizing strengths, confidence, belief in themselves, commitment to their family, trust and belief in each other were gleaned from the interview transcriptions. These were developed into the category of optimism for self and others, strong beliefs and the ability to endure. This category then amalgamated into the next theme of self-efficacy.

### *Self-efficacy*

The psychological characteristics of Ross and Brigit, such as, perceived self-efficacy, ability to handle stress and problem solving strategies, are attributes that have assisted this family in developing a healthy adaptation when faced with the adversity of parenting a child with autism. The capacity of the participants to believe in themselves has been an immense advantage for them. Brigit and Ross attribute some of their success to parent and family-based intervention programs designed to support families with a focus on parenting cognitions.

Ross and Brigit exhibit self-confidence and assurance in the techniques they use to parent both Brayden and Paige. They maintain a positive outlook and display

competency in their parental role. This competency is noted in the well-adjusted manifestations of both their children. Enhanced parental self-efficacy is associated with general family well-being (Dunlap & Fox, 1999). When asked to describe the personal attributes that contribute to his success in parenting a child with autism, Ross speaks about these characteristics:

*I am very goal-oriented. I am able to focus on the ultimate goal, and not get overwhelmed with the insignificant, often unimportant details. I can handle unexpected things coming on. So I am able to stay true to what is ultimately most important. For example, I don't get all worried about how an unexpected visit from my parents might affect Brayden. I am able to see that he does enjoy seeing them and even if he is thrown a bit, he will get a lot out of the visit (Ross).*

Resilience does not come from rare and special qualities but is drawn from an inner strength (Masten, 2004). It involves taking action and using your strengths in a proactive way when faced with challenges (Alvord & Grados, 2005). Brigit recognizes that she has these skills that attribute to her resilience and explains how she uses them to her advantage:

*By nature I am more patient with children than I am with adults sometimes...I recognize in myself that I just tolerate the behaviour of children in a positive way. I can see the good in people and situations. That has been a plus...really that has helped a lot. I am able to remain calm and empathetic. I understand that what I can control I do and what I can't control I just go with the flow as best I can (Brigit).*

Ross and Brigit suggest that life is not going to be easy or predictable when you parent a child with autism. Their capacity to remain calm and creative when problem solving is a powerful quality. The problem solving skills of this family enable them to identify controllable and uncontrollable circumstances and prepare for them as necessary. Dunlap and Fox (1999) list the parent's ability to problem solve as one of the most

valuable assets because belief in your ability to strategize increases self-worth and self-confidence.

Ross and Brigit's self-esteem is enhanced, as they are able to recognize these successful attributes in themselves. A family's ability to recognize their personal strengths is invaluable (Alvord & Grados, 2005). Ross speaks about the positive aspects of their lives together as a family unit:

*A strong and stable relationship keeps us on an even keel, even when Brayden and Paige's behaviour or activities throw monkey wrenches into the gears. I try to give my wife as much support as possible during these times, so that we are able to best meet their individual needs (Ross).*

Ross and Brigit understand that parents need to gain confidence in their own abilities. They work together and draw strength from one another. In a quantitative study, Heiman (2002) determined that love, joy, acceptance, confidence and strength are the prevailing attributes to success and resilience when raising a child with special needs. Brigit offers this statement as a reflection of her self-confidence:

*As a parent of a child with autism, you are going to have a lot of days where you wonder if you can do it or if you are doing it right but for the most part, you are doing the best you know how. You should do the best you can and take pride in how well you do for your kids. That is something to be very proud of. You have to remember that your child loves you and recognizes that you are the person that they can count on even if they can't tell you sometimes that they love you. Even if my child can't tell me that he appreciates all that I do, I know deep down inside that he loves me and trusts me (Brigit).*

Heiman (2002) proposes that it is a great societal benefit to understand the resilience, strength and positive relationships among the family members of children with special needs. Important elements of effective communities are environments that promote resilience for families (Alvord & Grados, 2005). Ross presents these details

about his thoughts of their strengths in parenting not only a child with special needs but also of ensuring the needs of their daughter:

*It is difficult to specifically identify how we ensure all needs of all of our family members...Brayden has always had autism. Our family dynamic has evolved in that way, it has been an evolutionary process. We just simply try to do our best for everyone in our family. We need each other and have a commitment and a connection to one another (Ross).*

Ultimately, families are their child's most influential life long resource (Dunlap & Fox, 1999). Brayden demonstrates his healthy adaptation in the fact that he feels security, warmth and love from his family. Brayden has difficulty with answering questions. However, when you witness how well he functions despite his daily challenges, his personal resilience becomes obvious. Many children with autism are fraught with anxiety and sensory issues which inhibit their ability to successfully integrate into the mainstream school programs. Others spend a large percentage of time outside the classroom with an educational assistant. Conversely, Brayden functions well in the classroom setting with the proper support. There are modifications such as visual schedules and educational assistance but with these supports he is able to sustain a fundamental education. He also has the ability to attain positive peer interactions. Several children with autism have great difficulty communicating successfully and thus peer interactions become strained. Brayden has the benefit of parents who aid in facilitating positive peer interactions by teaching him appropriate social skills and setting up play sessions with positive role models.

Resilience in children is obtained from forming exceptional relationships with positive role models (Alvord & Grados, 2005). Ross and Brigit are exceptional role models of resilience. Their resilience is represented by their manifestations of positive

adaptation despite significant life adversity (Luthar, 2003). Resilience in children is demonstrated by their capacity to overcome personal vulnerabilities and stressors (Luthar, 2003). Brayden demonstrates his resilience in his ability to function successfully within his family and also in the inclusive classroom. When discussing school relationships Brayden had this to say:

*Kids in my class should know that the rules are the rules.....they should get along perfect, not bullying, behaving and following rules (Brayden).*

Brayden portrays his healthy adaptation by the way he expresses the love and assurance of his family. Ross and Brigit know that Brayden needs individualized support and encouragement to succeed. His impairments in communication and social skills increase the difficulties he has adjusting to life. However, despite his many challenges, Brayden is well adjusted and plainly depicts the support of his family. When asked to describe his family Brayden simply stated:

*Oh it's great! Yes, and it is beautiful... I like to draw pictures with my sister and just play... I just spend quality time with my Mom and with my Dad I do lots of stuff, like going to Home Depot to buy stuff for our house (Brayden).*

Along with meeting the challenges of the child with autism, parents often find themselves working hard to help their other children adjust (Weis & Harris, 2001). Weis and Harris (2001) suggest that parents frequently struggle with issues such as when to tell the sibling about autism, how to explain the atypical behaviours and how to meet all the needs of individual family members. Siblings of children with autism are not always well adjusted. Resilience for children rests in positive relationships (Luthar, 2003). Paige undoubtedly has a positive relationship with her parents. Luthar (2003) explains that positive relationships are integral for achieving and sustaining resilient adaptations.

Children in a safe and positive environment demonstrate their resilience by showing respect and compassion for others (Alvord & Grados, 2005). Paige is only six years old but is nevertheless a respectful, empathetic and kindhearted young lady. Her empathy and consideration is demonstrated in this statement:

*My friends at school should know that you don't need to run away from Brayden, he won't hurt you. He won't hurt you unless you bother him much. If you are kind he won't hurt you. If I bring a friend home there are some rules like don't turn off the T.V. if he is watching it. Brayden will feel mad if you turn off the T.V. and then he might hurt you a lot if you turn off the T.V. We also have to let Brayden do his jobs and we don't bother him when he is working. That's probably it (Paige).*

Children become self-assured when they have strong and confident role models. By modeling respect, caring, empathy and understanding, the parents have clearly demonstrated these skills to their children. The confidence and sense of self noted in Paige is illustrated in this statement:

*My family is lots of fun. Especially when we go on trips. I also like to draw pictures with my brother. I am the greatest artist. My brother taught me and then he taught me too much because now I am the greatest (Paige).*

Ross and Brigit have taught their children cognitive problem solving skills by talking out situations and helping their children to identify the appropriate steps needed. They have encouraged their children to express their positive and negative feelings. Alvord and Grados (2005) explain that emotional distress after traumatic events is normal and that children need plenty of opportunities to talk about their concerns. Brigit and Ross have empowered their children by teaching them to talk about their trials. When asked what he would do if someone was bothering him on the playground, Brayden explained how he would solve the problem:

*I have autism so I think they should treat me nice. If someone were bullying me I would shout stop bullying me! I should tell the teacher if someone is mean to me (Brayden).*

Alvord and Grados (2005) elucidate that teaching children to be optimistic when judging their accomplishments is another important tool for children to have and will contribute to their resilience. Ross and Brigit have taught their daughter Paige to be understanding, respectful and considerate of all children, despite differences. Harris and Glasberg (2003) explain that siblings of children with autism often mature early and have a greater self-identity. Paige demonstrates her maturity with the empathy she has for others. Ross speaks about the resilient qualities in their daughter Paige:

*She is a strong person. She has gone into the world and is the first to welcome someone if they are new to the classroom or the school. She will go right up and be the first partner to someone who is in pain (Brigit).*

*Paige is mature. She has learned that sometimes her brother has outbursts but at the end of the day she is calm and collect about it and doesn't let it get to her. I think we have done well raising her (Ross).*

A strong sense of self-efficacy enhances an individual's accomplishments and their personal well-being (Bandura, 1997). People with high levels of personal assurance approach complicated situations as challenges to overcome (Bandura, 1997). Ross and Brigit exhibit this high level of assurance by the way they rise to the many challenges and stressors in their lives. This family reveals self-confidence, which provides them with the strength to endure despite adversity. This sense of self-efficacy contributes to the resilience of their family. The strength, determination and vitality they emanate have progressively developed from their sense of assurance. These factors have evolved into the next theme.

The interview question: “Please describe your characteristics or strengths that you feel have attributed to your success in parenting both of your children” led to significant units of meaning such as thankfulness, humbleness, optimistic hopes and dreams, commitment to each other and the parent’s ability to advocate for Brayden. These responses led to the category of patience, gratitude, humility, commitment and vigor. These attributes were used to develop the theme of strength and determination.

### *Strength and Determination*

Harris and Glasberg (2003) explain that several families of children with autism demonstrated an impressive sense of resilience and strength in their experience, learning to balance hard demands with grace and humor. Ross and Brigit have learned that the ability to laugh and see the humour in incidents is important to maintaining balance. Humour can be an excellent healing and coping tool in times of stress (Alvord & Grados, 2005). Brigit demonstrates her sense of humour when she describes a recent situation at school:

*To me this is normal but others must look at my life and think chaos! When I walk down the hall at school and my kids start running ahead of me I say; ‘stop’ and they don’t stop. For other people, they would just say ‘stop’ and their children would stop. Not so much with mine, it would seem that they would speed up! (Brigit).*

Brigit and Ross convey knowledge, strength and fortitude that assist them with future planning, goal setting and creating balance in their lives. There were numerous examples in the interviews of strength and determination that illustrate the resilience of this family. Ross metaphorically refers to Brigit’s strength:

*Brigit has undeniable strength. My wife shoulders much of the day-to-day responsibility for the children and the household. The children can always depend on her; she is the rock that Brayden can crash into (Ross).*



The strength that Brigit and Ross have is due in part to their dedication to their family. Their firm sense of prioritizing family is fundamental to their success. Children feel safe and secure when they live in a positive welcoming environment (Luthar, 2003). Ross illustrates the family's positive atmosphere and his devotion to his children when he describes his relationship with them:

*To me, Brayden and Paige mean the world to me. They know that and find comfort in knowing that their Dad loves them unconditionally. I see a lot of myself in Brayden. I think he and I enjoy a lot of the same things, such as computers and building things...learning how things work. He likes details and I am a details person also. I know that as he grows older, we will find even more common interests to share (Ross).*

Many parents struggle with parenting a child with autism and feel frustrated and overwhelmed with life's challenges (Harris & Glasberg, 2003). Brigit and Ross do not display this sense of turmoil in their everyday lives. Conversely, they reveal a lifestyle that is inspiring. Brigit exemplifies strength by sustaining her high level of success throughout the arduous daily responsibilities of parenting a child with autism. When asked if having a child with autism impacted the size of their family, Brigit offers this perception on the arrival of their second child:

*Paige was a planned pregnancy. I am grateful that the pregnancy with her coincided with not having a formal diagnosis for my son. I think I would have hesitated to have another child, not knowing if I could have handled two children with autism. It would have been an overwhelming thought. As it turns out, I would have gladly accepted another child with autism. I'm grateful that I didn't know and didn't have to make that decision because now we have this wonderful daughter in our lives (Brigit).*

Dunlap and Fox (1999) clarify that in a unified family environment in which caregivers are confident and support each other, the benefits to the child are maximized. They suggest that if a family environment is chaotic and discouraging, the outcomes of

the child with autism are greatly compromised (Dunlap & Fox, 1999). Ross and Brigit understand that the strength and security of their family unit is conducive to their healthy adaptation. Brigit articulates her thoughts about the commitment she and Ross have to one another:

*We have made a conscious effort and choice to remain a family unit. It's something we work at, it's not a given or something that we take for granted. We take a lot of pride in it and we hope that we are showing this to our children, and giving them a good role model for how a family can be even under stress (Brigit).*

Alvord and Grados (2005) explain that one of the ways in which resilient people display their inner strength is in their ability to self-regulate their emotions and behaviours. The parent participants display an inner strength by consistently exhibiting their calm demeanor, even in times of stress. In a recent terrifying incident when Brayden wandered away from the playground at school and was missing for several hours, Ross and Brigit remained incredibly calm and in control of their emotions. They quickly mobilized into action and used their problem solving abilities to assist in finding him. Inner strength is verified in their commitment to continue and to forge on despite all of the fear and trepidation that come with their daily challenges. Ross describes the strengths that have attributed to their success and resilience in this way:

*The most positive step that we have made in our family commitment was to reaffirm our relationship. A strong and stable relationship keeps us on an even keel. Prioritizing what is important to our family and household, sticking to the plans and executing them. Getting on the same page as my spouse, and keeping the lines of communication open. Defining roles within the household and accepting and maintaining them have been an asset to us (Ross).*

Social networks, informal support and professional interventions greatly improve the quality of life for families affected by autism (Renty & Roeyers, 2006). Brigit and Ross have accessed support programs, advocacy groups and the informal support from

friends. They have limited access to extended family support due to unexpected and uncontrolled circumstances. Brayden's maternal grandmother passed away when he was very young. Brigit's father as well as Ross' parents, live at a significant distance for most of the year, returning only for the summer months and for a brief time at Christmas. Brigit and Ross have only one sibling each who also both reside at a distance. With regards to the lack of immediate family support Brigit reports:

*With extended family, some people have it a little more relaxed but we don't have that. We have just had to learn to deal with that. It was sink or swim for us. I had to learn to do things for myself. I would definitely have loved to have more support! It just didn't happen (Brigit).*

Brigit does not consider her ability to sink or swim as strength. She often resorts to viewing her life and accomplishments with a sense of modesty and humility. However, the researcher considers this ability to adapt without extended familial support as a powerful strength and ability.

As observed through the course of the interviews as well as during our informal conversations that followed, both Brigit and Ross have demonstrated an undeniable strength and vitality. Friends are often considered the family that people choose for themselves. In this light, they seem to have a talent of attracting good people to them. This brings us to the last stretch of their road to resilience.

The question: "Can you illustrate the impact of having a child with autism on inter-family relationships?" brought about consistent units of meaning. Examples derived from the interview transcripts were: the need to surround themselves with good friends and people that support or uplift them and accepting assistance from the community, family and school. This category then advanced into the theme of support from family or community.

### *Support from Family or Community*

Supportive social networks predict better outcomes in healthy adaptation in families faced with adversity (Renty & Roeyers, 2006). Moral or psychological support from family or community offers an essential contribution to the resilience of the participants. Sivberg, (2002) agrees that resilience can emerge for families faced with adversity with support and proper intervention. Appropriate intervention and support has aided this family to mitigate the feelings of stress, guilt and vulnerability associated with autism (Stern & Bruschiweiler-Stern, 1998). However, as previously conveyed, the participants have limited contact with extended family. As a result, they have gathered the bulk of their support from their community of friends when family is unavailable. Brigit describes the process or adjustment period that is often necessary when they meet new people. She does not seek sympathy or commiseration from others but rather desires a sense of normality:

*Many people are fearful of Brayden's outbursts. They are fearful for their children so they don't like having play dates. People are fearful of what they don't know and so it makes them hesitate. I try to help them understand. Until they actually take the step and say okay and reach out, it is difficult. I was alone for a long time but now I have supportive people around me. I have found that I have met more friends who are teachers and they seem to have a better sense of differences in children and tend not to be as fearful. I have people around me now that seem to understand why I am doing some of the things that I do. When I have to modify his day, when there is a change in routine, they accept that. It is a rare person and a good person that can just act normal with you and know that Brayden shouldn't act out but also understands when he does (Brigit).*

For most families, help is accessed informally from extended families and friends (Dunlap & Fox, 1999). These participants have been encouraged and their sense of order has been re-established with the assistance from friends, family and other support groups. When Brigit's father is available, she welcomes the time that he spends with Brayden's

sister Paige. Paige will sometimes attend special events and outings with her grandfather. Excursions such as the Children's Festival or a football game would be unsafe or too over stimulating an experience for Brayden and so Paige's grandfather spends time alone with her at these events. Brigit expresses her views about these excursions and the strength and resilience evident in her young daughter:

*Paige knows that she gets to attend functions with her Grandfather when her brother isn't able to go because he couldn't handle the outing. She knows that life is a little easier for her, she gets to do things that her brother cannot. She can go to a friend's house without her Mom having to be there and these opportunities make her feel very independent and very confident. I take great pride in the fact that she is self-sufficient. She is independent when she wants to be but still feels that she has me to come to (Brigit).*

When caregivers know more about autism, the family has a greater sense of assurance and a higher quality of life (Bennet et al., 2005). Extended family needs to understand that parents of a child with autism experience an incredible amount of physical and psychological stress. Ross explains how he educated his parents to understand and appreciate the difficulties associated with Brayden's autism:

*Brayden's unpredictable behaviour can sometimes be a challenge. It can be frustrating when you think that he has understood what you expect from him and then he turns around in the next minute and does the opposite. I have tried to help my extended family understand this and the types of constraints autism places on our family, so that they are more understanding towards our need to control aspects of our daily lives (Ross).*

Social supports that are deemed useful for families include counseling for parents and their children, effective early intervention programs for the child with autism, social resources and family support groups (Heiman, 2002). Ross and Brigit have accessed the early intervention programs available for children with autism and in the past have used support groups to deal with Brayden's autism. Ross recalls that attending a family support group assisted him with coming to terms with the Brayden's autism:

*There is no official diagnosis on either side of the family, but I've come to believe that I may have been diagnosed with Asperger's syndrome. Initially I had difficulty dealing with Brayden's diagnosis until I later went to a parent meeting and heard other parents discussing their children. I noticed myself in their comments about their children. Brayden thinks and reacts in a similar fashion to how I think and react. We both recognize patterns and are good with numbers. I recognize that I have considerable quirks to my personality, which to some may seem anti-social. Making that connection was important to me (Ross).*

Sivberg (2002) suggests that parents need to fully increase their knowledge about the phenomena of autism in order to effectively manage the upbringing of their child. The literature highlights that empowering parents by sharing the skills and knowledge proven to be successful and encouraging them to gain the confidence to do some problem-solving on their own can be conducive to the healthy adaptation of a family under stress (Bailey et al., 1986). Knowledge equals power and can motivate parents to be the greatest asset to their children. Parental support programs can bridge the gap in understanding and offer problem-solving strategies (Heiman, 2002). Ross and Brigit are constantly reading and researching autism to learn all that they can. Ross lists the supports that they have used to assist with their constant pursuit of knowledge:

*The number of professionals involved since the initial diagnosis is vast. The diagnosis and future programming was made with the assistance of a speech and language pathologist, psychologist, pediatrician, social worker, occupational therapist and educators. Their assistance with the diagnosis was a gift. It gave us the context to do our own research to better understand Brayden's disability (Ross).*

Brigit clarifies that support and assistance were vital to their well-being. She recalls that although the support groups were powerful tools to assist with understanding and acceptance of the autism, it was sometimes difficult to access them. She remembers feeling a sense of isolation during the time immediately after the diagnosis:

*I don't like to focus on the negatives, but in the beginning it was definitely a very lonely time. There were support groups to go to, but then you would have to find*

*somebody to watch the kids. It was important, though. With other disorders, you can warn or predict what the child's behaviour is going to be like. With autism there is no telling from day-to-day or child-to-child what the disorder is going to manifest itself like. I learned that children develop differently, it is entirely up to them and that is okay (Brigit).*

It is important to find a support group or support system that works for you. The availability of a strong support system can assure a more positive familial impact (Alper, Schloss & Schloss, 1994). Ross and Brigit explain that some people may need more support than others. Success will not look the same for everyone; however, the critical point is to create a balance and personal meaning for you. They suggest that a support system can assist families in finding and maintaining balance in their lives. They emphasize that as the primary caregivers of a child with special needs, it is necessary to remain strong and healthy, to take care of yourself too.

Research suggests that the behaviours of the child can be difficult to deal with in the controlled area of the home but can be especially upsetting in public (Quill, 2000). For the family with a child with autism, lack of social assimilation or ability to fit in can cause turmoil (Krausz & Meszaros, 2005). When families with a child with autism go out in public, some family members may become embarrassed if the child exhibits strange or atypical behaviours. Ross and Brigit have often noted that if Brayden has an outburst in public, onlookers tend to judge or blame them. Dunlap and Fox (1999) explain “the juxtaposition of the child’s physical typicality and extreme behavioural deviance can make a parent’s humiliation even more acute” (Dunlap & Fox, 1999, pg. 3).

In a qualitative case study, Dale, Jahoda and Knott, (2006) resolved that mothers of a child with autism suffered from feelings of isolation and depression. Brigit

eloquently depicts how separated one can feel when your community doesn't support you:

*I have caught the looks in the halls at school. Even though others say, 'oh it's fine', you know that when I am dealing with one of Brayden's outbursts people stare at me and probably talk about me. A lot of times people are very polite and they turn or look away when Brayden is having an outburst. I know that they don't understand. They pretend that they don't see the disruption, or see my son hitting me, or yelling and I know that they do. I would rather people ask about Brayden. I know people are fearful of the unknown. I am getting better at letting go of how people look at us and judge us when we are out (Brigit).*

Family members can be encouraged and their sense of order or control can be re-established with assistance from community, extended family, and friends (Naseef, 2006). The role of social supports accessed by this family significantly contributed to their reduction in stress and coherence. The following passage was a candid offering from Brigit during the course of the second interview. This statement depicts the significance of support from a friend:

*This past year an individual came into our lives that just naturally understands and acts as if Brayden is any other child. He will speak to my son and interact with Brayden as if he was his own child. He doesn't accept the physical outbursts or pretend that they didn't happen. He'll try and correct him, not discipline but...guide maybe. He will change the subject or get him thinking about something else. He is very helpful to me at school. He will offer to take my daughter or redirect her to where she needs to be. Just that simple act, for five minutes in a day, is enough for me to feel validated, to feel normal, to feel like I am not the freak amongst the norm (Brigit).*

Resilience refers to either “the state of well-being achieved by an at-risk individual or the characteristics and mechanisms by which the well-being is achieved” (Ungar, 2004, p. 346). Ross and Brigit achieve well-being for their family by maintaining confidence in their decisions and abilities, accessing supports and balancing the priorities for their family. When asked of their hopes



and dreams for Brayden, they reported a desire similar to that of any parent, that their son be happy, healthy and confident:

*My hopes and dreams for my son are that he discovers what really intrigues him and that he pursues it with all available vigor, and that he finds peace in himself with his pursuits (Ross).*

## Summary

The first question postulated for this phenomenological study was: What factors contribute to the resilience experienced by a family affected by autism? The results of this study have identified six themes common to the lived experience of the parents and the recurring themes of healthy, well-adjusted confident children. It is important to identify the elements that attribute to this family's resilience. A goal in the analysis phase of phenomenological research is to develop the participant's experiences into a story that clearly depicts the main themes of their journey (Dey, 1993).

The story of this family of participants is that they share many of the same challenges, frustrations and stresses but also feelings of unconditional love, hope, caring and security. Their resilience can be defined as a "phenomenon characterized by good outcomes in spite of serious threats to adaptation or development" (Masten, 2001, p. 228). The challenges of parenting or having a sibling with autism are immense. Consistent with the findings of Miller and Sammons (1999) some of the difficulties identified by Brayden's parents include: his ritualistic behaviours, his resistance to change, the disparaging aggressive behaviour towards his mother and sister and the sacrifices Paige has faced due to restrictions in their family life activities.

The second research question was: In what ways did the family overcome the challenges of autism? Brigit and Ross face many struggles in their daily lives. Bristol

(1984) explains that children with autism present more disruptions to family routines such as meal times, outings and vacations than children with other disabilities. Taking an individual with autism out into the community can be a source of stress for parents. People may stare, make comments or fail to understand any mishaps or behaviors that may occur. As a result of these potential experiences this family does not always feel comfortable about taking their child to the homes of friends or relatives which can make holidays an especially difficult time for them. Feeling like they cannot socialize or relate to others, the parents on occasion experience a sense of isolation from their friends, relatives and community. As such, autism could be considered a disorder of the sense of family (Rapin & Wing, 1988). However, Brigit and Ross have endeavored to overcome these negative trajectories.

It is the family as a whole that is greatly affected by autism. Turnbull and Turnbull (1990) clarify that whatever the experiences of one family member are, these will affect and influence the entire family unit. The experiences of Brayden's life are not restricted to him but are in fact experienced by all members of the immediate family (Krausz & Meszaros, 2005). Despite their many trials, the participants in this study have demonstrated strength, determination, confidence, acceptance, adaptability and gratitude.

The final query was: How or what can other families learn from this family? The family of participants clearly depicts a success story. What the researcher has learned from this study is that resilience in families affected by autism can emerge. The emphasis of phenomenological research is on the world of the participants and how they live it, this family's resilience is evident in the manner in which they conduct their daily lives. Stevenson and Zimmerman (2005) explain that "resilience refers to the process of

overcoming the negative effects of risk exposure, coping successfully with traumatic experiences, and avoiding the negative trajectories associated with risks” (p. 399). The participants in this study have demonstrated their abilities to overcome, cope and avoid the negative outcomes most often observed in families affected by autism. With candor Brigit enlightens the reader with this excerpt:

*You have to remember that your child loves you and recognizes that you are the person that they can count on even if they can't tell you sometimes that they love you. Even if they can't tell you that they appreciate what you are doing. You have to know that deep down inside they love you and they trust you and they need you. The nicest thing is that I have never felt as much unconditional love from one person as I have from my son. He is my heart, because he doesn't have a mean spirited bone in his body. He is pure. He doesn't do things because he expects something or because he knows he is going to get something in return. He just acts from his heart. We need each other and I have never felt as deep a commitment or as deep a connection as I do to Brayden. That is special and I like to think that we have been brought together for a reason and that he is meant for me and I am meant for him. We are in this together. He is there for me as much as I am there for him. He is my hero. There is nothing that I cannot do because if Brayden can handle all of the frustrations in his life, so can I. This is a gift that I never expected but I cherish it (Brigit).*

The concept of resilience is most often applied to an individual but the participants in this study demonstrate unified resilient family dimensions. Resilience has enabled these participants to function and to maintain their morale and optimism during times of crisis. The resilience and strength that they bring to their experience demonstrates that they have learned to cope in a productive, well-adjusted manner. These participants are strong, vibrant family members and it is their healthy adaptation despite adversity that will prove to be one of the greatest prevailing resources for their son.

## Chapter Five

### Discussion

#### Overview

The final chapter represents the researcher's account of the experience of conducting this phenomenological study. The purpose of the study was to explore the lived experiences of a family affected by autism. This chapter will reflect the findings and lessons derived from the interviews with the participants and the continual process of investigation and analysis throughout the course of the study. Analysis of the themes consistent among the parents, and to some extent the children, will be considered, as well as, an understanding of the need for further learning and development are addressed in this chapter.

#### Discussion

The inquiry process of this study allowed the researcher to capture the scope and magnitude of the participant's experiences living in a family affected by autism. The researcher was able to develop an appreciation and awareness of the realities of living in the midst of a child with unique and often overwhelming needs. The researcher's understanding of the lived experience was enhanced as a result of the participant's candid responses during their interviews. The following are the reflections of the researcher who found possible meanings and divergent perspectives of the lived experiences of the participants. It is the opinion of the researcher that it is of greater value to examine the strong and constructive families affected by autism than to observe those who are consistently fraught with conflict. Consequently, an interest or curiosity with regards to autism and resilience began when the researcher first met the participants several years

ago. Through experiences and observations as a special education teacher, the researcher had theorized that this family demonstrated a healthy adaptation and anticipated that these resilient qualities would surface through the course of the interviews and subsequent analysis.

Questions were carefully selected and phrased in advance to elicit maximum responses from the participants. The function of the questions for the parents was to identify the factors that contribute to their resilience in parenting a child with autism and to discover the ways in which they have overcome the associated challenges. The purpose of the questions for the children was to glean from them the factors that contribute to their healthy adaptation, fervor and zest for life that they exhibit. The researcher strived to discover what could be learned from the successes of this family of participants. The task of the qualitative researcher is to find patterns within the responses of the participants and to present those patterns for others to examine, while at the same time remaining as close to the construction of their experiences as they originally experienced them (Shank, 2002). The following is a breakdown of the findings of the research questions.

## Findings

### *Researched Based Outcomes After Diagnosis*

The diagnostic impact of autism presents significant challenges to parents in terms of everyday organization and lifestyle. Dale, Jahoda, and Knott (2006) attribute the child's maladaptive behaviours and unknown prognosis to the significant levels of stress endured by parents. The interviews revealed the difficulties in parenting are long-term and may include: distress due to their son's disparaging behaviours, the constant need for

problem solving and the ambiguity of the disorder's course and prognosis itself. A high prevalence of guilt is due in part to the fact that the primary cause of autism is still unknown (Hallahan & Kauffman, 2006).

The typical expected outcome according to Bristol (1984) predicts parents of children with autism include: fatigue, depression, lowered self-esteem, and interpersonal dissatisfaction. The parent participants in this study have experienced many of these hardships, noting struggles with self-doubt, trepidation, times of depression and extreme fatigue during their interviews but have managed to prevail despite these personal hardships. Weiss (2002) determined that mothers of children with autism had a higher rate of depressive symptoms than mothers of children with other disabilities and mothers of typically developing children. When acceptance and understanding are inadequate, parents and their children with autism can become isolated due to their family's constant state of stress and uncertainty which can cause a negative influence on family coherence (O'Brien, 2007). The participants in this study have maintained their compassion and understanding for their son and continue to exhibit a strong family coherence.

According to Guillermo and Halterman, (2007), who surveyed three hundred and sixty four mothers of children with autism, these mothers had considerably higher levels of parenting stress than mothers of typical children. They noted that maternal stress was influenced by the intensity of the child's behaviour problems and his/her ability to communicate. Successful samples in the group were found to have the commonalities of parental support and an aptitude in parenting skills (Guillermo & Halterman, 2007). The participants in the current study demonstrate these strong parenting attributes as well.

Their strengths in parent-child relationships, coping strategies and support have significantly reduced the negative trajectories of parenting their child with autism.

The researched based outcome for the participants would be an existence burdened with the numerous stressors associated with having a child with autism (Sivberg, 2002). Fortunately, the participants in the study have not been overtaken by stressors but rather have emerged with the ability to withstand and rebound from crisis. These parents have been able to thrive despite the adversity of parenting a child with autism. Among other unique attributes, their resilience is due in part to the causal factors of: acceptance, understanding, adaptability, strength, determination, self-efficacy and the support of friends and family.

#### *Family Characteristics*

Acceptance of autism and an understanding of its manifestations are necessary for the healing process to begin, as the grief can seem overwhelming to families upon first hearing of the diagnosis (Naseef, 2006). The initial grief associated with the loss of the dreams for their child was a significant loss to the parent participants. However, they realize that when negative events are perceived as uncontrollable these feelings can lead to thoughts of helplessness. The parents recognize that they had the influence to problem-solve to come up with strategies, thus the typical outcome was altered. The parents described the process of acceptance as empowering. They used this process as a positive personal development that directed them to concentrate on learning new skills such as research and advocacy.

It is important to acknowledge that acceptance and understanding have steep ongoing learning curves and are not an ultimate end result (Klar-Wolfond, 2006).

Acceptance and understanding in the community can be enhanced by advocacy for inclusion in the classroom with the necessary adaptations to meet the needs of each child. In this respect, what can be learned from these participants is that empathy and acceptance of all people regardless of differences is ultimately valuable for the whole community. Klar-Wolfond (2006) maintains that an increased knowledge and understanding about autism in society will lead to greater respect, dignity, tolerance and support from community for people with autism. As educators, and society in general, it is critical to continue to support the acceptance and inclusion of children with autism.

Communities should make every effort to value the unique struggles of a family affected by autism (Rapin & Wing, 1988). The participants demonstrate their strength as outstanding advocates for their son. Advocacy can be a means to achieving improved services for children with disabilities as well as providing a sense of control over outcomes for the parents (Hallahan & Kauffman, 2006). The participants have utilized this skill to access programs, therapies and educational assistant for their son. They also attempt to educate other parents in their school community, their extended families and the community in general.

The acceptance of the parents was achieved by educating themselves and their children about autism. The parents learned the importance of maintaining consistent, unified goals to ensure the fundamental success of their family life. Education and understanding has assisted them with interventions, such as tracking behaviour patterns and anticipating situations that will elicit negative trajectories. They have learned through research that proactive strategies can be incorporated into their daily lives to support their home environment. Heiman (2002) maintains that the three factors that



contribute to parent's acceptance and understanding are: 1) open discussion with family, friends and consultants 2) supportive positive bond between parents and 3) continuous educational, professional and psychological support for the whole family. Once acceptance has been achieved, the motivation to develop understanding stems from compassion rather than anxiety (Klar-Wolfond, 2006). The interviews revealed that the parent participants have achieved the three factors outlined by Heiman (2002). Consequently, their acceptance evolved into a level of compassionate understanding for children with autism. The parents continue to openly discuss their son's needs with family and friends in an effort to evoke understanding, they actively cultivate family accord, they persist in refining their knowledge of autism and they seek support from their community of friends.

#### *Familial Subsystems and Family Interaction*

There are certain attributes that assist this family of participants in attaining more resistance to crisis. Consistent with Bristol (1984) some of their successful attributes include: self-assurance, cohesion, organization and adaptability. These skills have assisted the parents to prevail over many challenges of parenting a child with autism. Sivberg (2002) identifies flexibility, problem-solving capability, patience, understanding and a focus on the good qualities that come with autism, as being imperative to family success. The identification of these qualities is evident in the participant's interview responses. The parents demonstrate flexibility, problem-solving, patience, unconditional love and understanding qualities which have enabled them to emerge from the strain of parenting their son with dignity and resilience.

The parents consistently endeavor to create family stability by providing structure and routine to their daily lives. Routines provide the necessary framework for the development of children with autism (Quill, 2000). The data from this study verified the importance of being consistent with routines to maintain firm relationships with all members of the family. The parents maintain that children with autism need established consistent routines for enhanced family accord. If families become disorganized and distressed their child may respond to the confusion with unwanted behaviours such as aggression (Marcus, Kuncze & Schopler, 1997). The participants reported that to maximize their son's potential, stability and routine is vital.

One example highlighted by the participants is the vigilant preparation needed prior to transitional periods such as the beginning of a new school year. The parents aim to anticipate and avoid triggers for negative behaviour during times of altered schedules or routines to assist the coherence of their family life. The parents expressed during their interviews that explaining change repeatedly beforehand and in simple terms, helps to mitigate the effects of change for their son. This is consistent with research, as children with autism are easily confused or distressed by change (Wing & Potter, 2002). The participants report positive results using Board Maker picture cards to assist in easing transitions and bridging gaps in their son's understanding. This strategy was particularly valuable when he was younger. For young children or children with very limited expressive or receptive language, PECS can be an effective tool for communication (Quill, 2000).

If changes occur suddenly, and are upsetting to their child, the parents maintain all other life routines as familiar as possible to alleviate the strain. Consistent with the

participant's recommendation that casually accepting outcomes and remaining flexible when change is inevitable; Dunlap and Fox (1999) advise that flexibility and adaptability are conducive for cohesive family outcomes. Family cohesion refers to the extent to which each family member is able to achieve individual fulfillment apart from other members of the family (Hallahan & Kauffman, 2006).

The findings from the participants were consistent with the current literature. Sivberg (2002) analyzed survey results from parents with children that have a disability and concluded that: constant pursuit of knowledge, adaptability and consistency in parenting strategies significantly enhances the family's quality of life. The data revealed that the parents use these skills to overcome their daily challenges. They apply appropriate and consistent expectations for behaviour, develop their daughter's sense of empathy so she can understand her brother's unique needs, research innovations regarding autism awareness and possess the insight to alter personal schedules during times of transition or stress. The participants acclimatize their son to new situations or experiences to accommodate his needs and ease stress due to transitions. They allow time for him to adjust to new settings and demonstrate problem-solving ability in times of uncertainty or tension.

A study conducted by Weiss (2002) resulted in an understanding that fostering flexibility and adaptability in parenting strategies were important to success and healthy adaptation of families of children with special needs. The parent participants and their daughter convey this capacity to remain unscathed during trying times. They are well prepared for times of uncertainty but also remain flexible during life's tribulations. During their interviews, the parents described occurrences such as traumatic outbursts in

public that have required swift adaptations to personal agenda. Their ability to promptly evaluate and adapt to an unexpected situation demonstrates their flexibility.

Families with a child with autism face both the normal pressures and tensions of family life in addition to adjusting to the significant stresses of parenting a child with a disability (Heiman, 2002). The data revealed the family experienced all of the usual pressures and tension of family life. Their healthy adaptation is not due to the avoidance of these factors but is due to their ability to prevail. Reorganizing their lives to positively adapt is essential and ensuring that the needs of their entire family are met are contributing factors to their resilient family functions. Turnbull and Turnbull (1990) explain that each unique family is an interactive system and the distress of one family member influences or reverberates among all other members of the family system. The presence of the child with autism has in itself created challenges to their family life but has also impacted the inter-familial relationships.

#### *Sibling relationships.*

The children's relationship in this study has evolved, as they have grown older. Although the sister is the younger of the two, she possesses a greater maturity than her brother and is able to adapt to situations that require her to accommodate his needs. For instance, as was expressed in the interviews, her brother needs to be the first to experience new or exciting activities or he will have a physical outburst. This is often true of the youngest sibling in typical families but for this family, their youngest child is expected to be sensitive and understanding of her older brother's needs. Turnbull and Turnbull (1990) explain that siblings of children with exceptionalities experience unique issues and challenges such as potential long-term care responsibilities for their brother or

sister, future genetic implications for their own children and the responsibility to enhance the quality of life for their sibling. The occurrence of having a sibling with a disability may impact the child with emotions such as fear, anger, and guilt, which are similar reactions that parents also experience (Hallahan & Kauffman, 2006). Research indicates that siblings may additionally struggle with issues such as; contradictory expectations for themselves versus their sibling, anxiety related to their sibling's abnormal behaviours and reservations about how they will be perceived by their peers due to having a sibling with a disability (Hallahan & Kauffman, 2006). The parent participants in the current study demonstrated an aptitude to dispel the associated anxiety of their daughter, which enables and enhances their children's relationship.

*Parental contributions to inter-family relationships.*

The effects of the birth of a child with a disability can have profound effects on the whole family and thus the needs of all family members need to be measured (Gill & Harris, 1991). The parent participants reported that it is essential to take both children's needs into consideration when addressing issues that arise. As revealed in the interviews, the parents strived to treat their son as an equal member of the family and their conduct ensures that the needs of the entire family unit are met. Siblings and their needs should be planned for in the context of the whole family system (Gill & Harris, 1991). During the interviews, the parents highlighted the significance of the relationship between their children. They recognize that the positive interactions between the children are crucial to their family's healthy adaptation. As a result, the parents served as positive role models for developing the relationship of their children.

It was clarified in the interviews with the children that they both benefit from the dynamics of a healthy family system. The children convey their resilience in the manner in which they conducted their interactions with the researcher, their parents, each other and at school. The parents have ensured that the children are well-adjusted, strong and independent children. The data collected in the interviews indicated that the children function well at school, they have friends at school and outside of school and they demonstrate content and happy characteristics.

Siblings of children with autism can demonstrate a great sense of maturity and responsibility if exemplary role models are available to the child (Harris & Glasberg, 2003). As revealed in the interviews, the parents are commendable examples of character to both of their children. They scrutinize over decisions and consistently consider the needs of the whole family. How siblings adapt to the dynamics of having a brother or sister with a disability depends upon familial, psychological and personality influences (Alper, Schloss & Schloss, 1994). The parent participants have demonstrated to their children the attributes of strength, malleability, fortitude, independence and optimism. Siblings can become more grown-up and dependable as well as develop pride in their brother or sister's accomplishments (Powell & Ogle, 1985). The sister has the benefit of observing parent role models who are well educated about their son's disability, demonstrate problem-solving skills and are confident and self-assured in their decisions.

#### *Spousal relationships.*

The parent participants in this study made a decision to have the mother remain at home, however, this approach may not be appropriate for all families. There is no literature consistent with this as a common strategy. In fact, some parents may desire to

seek employment in an effort to offset the demands of parenting a child with autism.

What is consistent with the literature is that in order to compensate for stressful occurrences, parents need to find fulfillment or balance in their lives (Marglait & Heiman, 1986). Hallahan and Kauffman (2006) explain that families should attempt to create a state of balance within themselves, their families and their communities. During the interviews, the parents expressed the desire for balance in their lives as well.

Family and personal harmony are essential to the family system given that the parents will be the child's primary care giver and life long advocates (Dunlop & Fox, 1999).

Each individual family situation will be unique, however it is essential that all family members find personal satisfaction and achieve a high quality of life. The parents in this study stressed the importance of participating in activities independent of their children. The data collected in the interviews indicates that the parents make a conscious effort to create a harmonious and cohesive relationship with each other. Their marital intimacy and connection with one another has enhanced their lives and eased the tension due to the dynamics of having a child with autism. The parents also encourage their daughter to partake in opportunities and activities independent of her brother. As well, they have their son access fulfilling activities suited for his personal needs. As a result, they have been able to adapt their lifestyle to meet the needs of each family member and they have achieved a cohesive balance for all of the subsystems of a family.

*Familial accord.*

Krausz and Meszaros (2005) elucidate that the impact of having a special needs child is never restricted to the individual alone but rather all members of the family are affected as well. Harris (1982) explains that different subsystems within the family of a

child with exceptionalities occur. This involves the parents, the siblings and the child with autism. The research findings suggest that each subsystem among participants remains sound.

### *Character Strengths to Overcome Challenges*

The participants and professionals alike are consistent when referring to flexibility and adaptability as fundamental characteristics that increase family stability and strength (Sivberg, 2002). In a quantitative study of sixty-six mothers of children with autism, Sivberg (2002) determined that possessing the coping strategies of adaptability and flexibility had a direct correlation to a parent's ability to manage stress. The focus of the study was a parent's perception of the world and their cognitive ability to withstand stressful situations with emotional stability (Sivberg, 2002). Flexibility for the participants involves the aptitude to manage stress and acclimatize to changes in daily routines when they occur suddenly. As determined from the participant's interview responses, the parents have the skills to manage situations that are unpredictable. They possess personal attributes that enable them to adequately meet the demands when unexpected outcomes occur. Adaptability refers to the degree to which families are able to change their modes of interactions when they encounter unusual or stressful situations (Hallahan & Kauffman, 2006, p. 120).

The participants have also ensured that a sense of growth and accomplishment is maintained in their family despite the occasional setback or defeat when things do not go according to plans. Dale, Jahoda and Knott (2006) explain that if parents are skilled in making good decisions this will positively influence their effectiveness in parenting. Conversely, parents who blame themselves for their child's disability and feel helpless



may have limited success. A commonality between the research findings and the literature reviewed is that when families demonstrate a healthy adaptation or resilience, so do their children with autism (Falik, 1995).

Weiss (2002) in a quantitative study determined that the attributes most conducive to success in raising a child with special needs included the variables of self-efficacy, social support and marital unity. It was suggested that parents should become a positive activist for their child, learning as much as they can about autism to ensure that self-assurance, problem-solving skills and coping strategies continue to develop (Weiss, 2002). The parents have made every effort to maintain these characteristics. Baron-Cohen (1995) concurs that parents of children with autism will have to learn to seek out and campaign for therapies, technical assistive devices, school support for educational assistants and even specialized dentists and doctors. The parent participants have proven skills in advocacy when attaining school modifications, devices such as a personal computer to support their son's education, and when accessing therapies from an early stage in the diagnosis of their son.

The research findings indicate that families affected by autism can be strong, adaptable and capable of managing the challenges of parenting a child with autism. Hallahan and Kauffman (2006) reported that some families with a child who has a disability may have unanticipated positive results such as a greater tolerance for differences in others, improved parenting skills and a stronger sense of family unity. The parent participants have revealed these positive results in their interviews and have recommendations that other parents may benefit from. For example, the interviews revealed that having a child with autism has, in some ways, strengthened their family

bond. The participants suggest that caregivers should have realistic expectations for themselves, and propose that intense emotions emerge from the initial diagnosis but with time one can regain a sense of stability for their family.

Whitman (2004) explains that parents are often disoriented and that each person's experiences will elicit unique reactions and sentiments that will be real to each individual. The participants noted their personal experiences and proposed that occasionally, caregivers may be apprehensive or overwhelmed but that they may also be able to draw on an inner strength and become empowered to activate positive change if they endure. Therapists agree that all emotions are valid and are legitimate to the lived experiences of the individual (Alvord & Grados, 2005). The participants advise that it is essential for caregivers of children with autism to maintain their sense of self-efficacy, sense of humour and patience.

The Autism Society of Canada (2007) suggests that overanalyzing, or attempting to micromanage every aspect of the day can cause additional anxiety for parents. It was recommended by the participants that caregivers of children with autism understand that there is no precise, successful technique for all children. They recommend that although it is vital to research effective parenting strategies, they caution other caregivers that not all strategies are successful for all children with autism. The parents, therefore, suggest that other caregivers should use their own judgment when problem solving. Harris and Glasberg (2003) advise caregivers to take pride in their own abilities and celebrate the successes in their lives. Professionals recognize that parents have a wealth of information with regards to suggestions for the treatment of their children (Hallahan & Kauffman, 2006). As determined during the interviews, this family demonstrates a strong sense of

pride for their personal accomplishments of both of their children. They have identified the attributes and abilities that have been conducive to the resilience of their family.

The participants in this study have revealed a high level of optimism and inner strength in their pursuits and have a vigorous outlook on life. The responses collected from their interviews elucidate that both of their children are revered regardless of transgressions. The parents clearly and unconditionally love their children. Their family coherence demonstrates the positive balance that they have been able to maintain. The participants recommend that parents of a child with autism should strive to have an approach of gratitude in daily life. Psychological characteristics such as perceived self-efficacy and problem-solving ability are attributes that assist in feelings of personal success (Dunn et al., 2001). These factors corresponded with the participant's perception of their own family lifestyle. They recognize that personal aptitude is advantageous and conducive to family coherence. The parents realize that they have been successful in overcoming their many challenges and recommended that parents of children with autism should be grateful and appreciative of their successes, noting that a brief indulgence in self-pity or sorrow is acceptable but suggested that one must also learn to consistently celebrate accomplishments.

The researcher has derived from this phenomenological study that a family can be strong and malleable when faced with the trials of raising a child with autism. The family in the study has demonstrated strength and resilience in the ways that they have learned to cope with their son's adversity and challenges as a result of autism. Rapin and Wing (1988) explained that parents of children with autism may often be exhausted and frustrated from a number of issues which include: caring for the child, conflicts with the

child, lack of time and constant worry over the child's well-being. In addition, many children with autism may not be able to communicate his or her needs, leaving both the child and parent routinely frustrated. Daily tasks such as eating, sleeping through the night, playtimes with peers for both children and maintaining safety from accidents create unique challenges and have been highlighted by the parents as stress-inducing. This family's stressors are not unique but the capacity with which they have overcome is distinctive.

Parents who are able to succeed regardless of adversities exhibit an inner strength and determination. This family has prevailed over the grief associated with Brayden's autism, and their vigor enables them to continually progress notwithstanding the countless oppositions they face daily. Alvord and Grados (2005) agree that successful or resilient parents demonstrate the characteristics of inner strength and determination. The interviews have determined that in terms of individual characteristics, the strength and determination demonstrated by coping strategies appeared to boost the sense of purpose for these parents. The participants are dedicated to their children and have a keen sense of fortitude and aptitude in coping with conflict.

Gray (1992) advises that strength and coping strategies are important indicators of a parent's psychosocial well-being and result in reduced anger, anxiety and depression among parents of children with autism. During the interviews the parents described many effective parenting strategies that work for their son, such as the use of incorporating PECS, visual timers and allowing necessary time for him to complete tasks independently. The participants also made reference to the importance of remaining calm

and avoiding anger. Similar findings were found from Gray (1994) who noted that patience and empathy help to create a harmonious family environment. The participants illustrate that being attentive to their child's needs has been another influential factor in their emerging resilience.

The ability of the participants to be empathetic supports their family's cohesiveness. It has been imperative for the parents to anticipate situations that may cause emotional outbursts or distress. They need to be aware of their son's warning signs and circumstances that could trigger negative behaviour. The interviews revealed that the parent's consistency and their aptitude to guide their son through tasks nonchalantly with praise, greatly increases the coherence of their family lifestyle. Parents with difficulties in coping skills such as these have been noted to have increased anxiety and tend to be overprotective and rigid which can result in lower levels of coherence and less emphasis on personal growth (Heiman, 2002). The participants, in contrast, have decreased their anxiety and conflicts and have become a well-adjusted family.

### *Social Support for Families*

Social support refers to emotional, informational, or material aid offered to people in need (Hallahan & Kauffman, 2006). Research specifies that parents of children with a disability experience more than the average amount of stress in daily life but indicate that the strain of this occurrence can be compensated by appropriate intervention and support (Lessenberry & Rehfeldt, 2004). Parenting a child with autism can pervasively affect the entire family system (Hallahan & Kauffman, 2006). The participants revealed in their interviews that the overwhelming demands of their family life could at times be exhausting. Gill and Harris (1991) clarify that families who are able to access resources

to cope with challenging events are less likely to suffer the negative effects of the pressures involved when coexisting with a child diagnosed with autism. They conclude that families will be more adaptive and efficacious in parenting when they seek support programs that offer services such as cognitive-behavioural treatment (Gill & Harris, 1991). The participants have accessed support programs since the initial diagnosis and have demonstrated efficacious strategies with regards to their parenting and family life style as a result of these supports.

As indicated in the data, the parents have accessed the resources offered in our community to learn effective parenting strategies and to engage in dialogue with like-minded parents with the intention of growth, development and advocacy. Weiss (2002) discovered a direct relationship between hardiness and social support, noting that support from multiple sources strengthens parent's coping strategies and their sense of self-efficacy in meeting the demands of stressful situations. McCubbin and Patterson (1983) suggest that the strongest determining factor in a family's success when adapting to life with a child with autism is the support from their community. The participants have emerged from the difficulties of having a child with autism with a positive outcome in part due to the support of friends, family and community. When communities educate themselves and provide support for families the value of these programs is significant.

Bromley, Hare, Davison and Emerson, (2004) interviewed sixty-eight mothers children with autism and found that there was a direct correlation between physical distress of the mothers and their lack of family or community support. The participants reported that support from friends, family and community has assisted them at times when they felt isolated and distressed. Bristol (1984) affirms that social supports offer a

buffering effect to lessen the negative outcomes in families with a child with autism. It is best practice to arrange for interventions for the entire family through support plans (Dunlap & Fox, 1999). The parent participants in the current study have confirmed that family support providers can deliver extremely valuable assistance. They maintain that programs designed for children with autism and their parents have facilitated their confidence and improved their effectiveness in parenting. As indicated in the data, social supports such as informational or emotional assistance, have contributed to the healthy adaptation of this family.

Adaptations learned by the participants from support services include: a need for flexibility when unexpected circumstances transpire, personal self-efficacy or self-worth, the importance of intimacy and a steadfast commitment to one another and to the children, adaptability, strength, understanding, support, patience and gratitude. The family demonstrates these qualities when they encounter obstacles associated with raising a child with autism. For example, they may encounter obstacles such as physical attacks, noncompliance to social standards, lack of acceptance from community and limited expressive communication of their son. As indicated in the data, when barricades occur the parents implement the lessons learned during support groups to alleviate the tension.

Learning to accommodate the various challenges of the child with autism can be an arduous task. The chronic nature of autism can affect some parents negatively and there is a danger of becoming exhausted and pessimistic (Sivberg, 2002). Dale, Jahoda & Knott (2006) concur that the contributions of social support can offset or reduce the stress levels in families. Accessing treatment of societal services has helped the parents to

increase the manageability of their son's disparaging behaviours. Extreme behaviours such as physical outbursts and self-injurious conduct necessitate the access to extended family, friends and community. The participants report that these support systems have been crucial for maintaining harmony and coherence in their family's life.

The participants highlighted that friends and family members can assist in mitigating a family's stress when they readily offer support. Weiss (2002) determined that esteem-boosting friendships were predictive of less depression and feelings of greater personal accomplishment in parenting. The parent participants occasionally fail to share in the activities of their daughter in order to stay home caring for their son. They also indicate in their interviews that they do not have as many opportunities to spend time alone with each other as other couples. The parents revealed that they occasionally feel isolated by the constraints that the autism places on their lives. Considerate and understanding friends and family can help to encourage caregivers with positive remarks regarding patience, parenting skills and deeds of unconditional love for their children. The participants clarified that this type of support helped to alleviate some of the negative effects during particularly stressful times. The participants expressed during their interviews that the support from friends has been a prevailing contribution to their healthy adaptation.

It is recommended by the participants that families of children with autism can also derive tremendous strength from social supports offered by the school system and should therefore seek out the programs available in their community. The parents suggest that early intervention offered from educational programs for young children with autism is an invaluable resource.



### *Educational Support*

Heiman (2002) suggests that finding the best educational program available to fit your child's unique needs will alleviate familial stress. Early intervention programs offer special education opportunities for children with autism and have proven to be highly effective. The participants began accessing all available therapies and educational programming before their son was three years of age. It is crucial for parents of children with autism to contact the local school district or health department, or ask a pediatrician about preschool and educational programs that are available. As indicated in the data, working cooperatively with classroom teachers, educating classmates and their parents, use of visual schedule boards for communication and attaining education assistants are all examples of methods these parents use to assist with adaptations for the school settings.

The data suggest that positive benefits can occur when parents and teachers work collectively to meet the needs of the child. Educators should resolve to make a concerted effort to involve parents and families in the education of children with special needs (Hallahan & Kauffman, 2006). The data revealed that parents of children with autism can be an invaluable resource for educators, highlighting that good communication between school and home is vital. Frequent parent teacher conferences, regular informal conversations, as well as daily communication booklets, which travel to and from school on a daily basis, are strategies for communication used by the researcher. Applying the expertise of parents can facilitate the programming for children with special needs.

### *Benefit of Support Systems*

Research findings suggest the importance of utilizing all the positive support available from family, friends and the community. The above factors are consistent with

the literature that recommends that parents need to share their thoughts and feelings and should seek out someone whom they feel close to that will be understanding and supportive (Heiman, 2002). Bristol (1984) suggests that mothers of children with autism experience the least amount of stress when they received support from their spouses and relatives. The parent participants have educated their extended family on the subject of caring for children with autism to enhance valuable support from them. This has been empowering for them because extended family and friends are an invaluable source of support to families affected by autism.

In the literature, it is recommended that parents indulge in self-fulfilling activities (Bromley, Hare, Davison & Emerson, 2004). It was revealed in the interviews that it is vital for caregivers of children with autism to take care of themselves and that there is a direct relation between physical distress and a lack of support. Heiman (2002) suggests that parents often lose contact with friends and relatives because they become consumed with the trials and demands of their daily lives. The participants advise that in order to offset the stress of their lives it is necessary to have an outlet to relieve stress, such as a sport, fitness or leisure activity. The participants note that if they should fail to remain emotionally robust and healthy, they would have difficulty in maintaining a well-balanced family union. Quine (1985) suggests that if a parent feels overwhelmed, he/she will not be emotionally energized to guide and assist the child with autism. Participants reported that seeking out and surrounding oneself with compassionate and encouraging people can be advantageous to re-energizing. The parents are skilled in this respect and recognize how best to create a sense of balance in their lives.

The focus of this study has been on resilience when parenting a child with autism. At the inception of this phenomenological study, the participants were theorized by the researcher as seemingly resilient, and were therefore worthy of further exploration. This study has been an opportunity for the researcher to share insights into the unique experience of raising a child with autism. It has been a journey from a deficiency in understanding to an awareness, respect and identification of the attributes and characteristics most conducive to resiliency in a family affected by autism. Information gathered during the interviews clarified which factors contribute to the participant's resilience. The researcher gained background knowledge of the guiding principles the family has used to overcome many of the challenges of autism. As well, direction and insight intended for other families with a child with autism were recommended.

#### Limitations of the Study

This study adds to the body of existing knowledge by bringing attention to the implications of raising a child with autism but cannot create broad generalities about how families are affected. Reality is complex, constructed and ultimately subjective, therefore, the details of the experiences of the participants cannot be generalized to other contexts. Questions in the interview schedule related to specific feelings, emotions and personal strategies; the results of these findings are context bound and should not be generalized outside of this family. Although the results of this study are not intended to be generalized to other contexts, or families beyond the participants, certain findings may resonate with the experiences of other caregivers of children affected by autism.

As with any research, the results of this study are limited by several factors. First, the small sample of only one family of four is acknowledged, but is acceptable given the

exploratory nature of the study. Second, the sample consisted of a family who knew the researcher on a professional basis prior to the study and comments made during the interview process may have been more candid than if this previous relationship did not exist.

It should also be noted that the participants are an intact middle class family who are well educated and have access to resources that a family with lower socioeconomic status may not have. As well, participants who volunteer for a study may only represent a select group of individuals who feel comfortable talking about personal experiences. It would have been valuable to access participants from varied backgrounds, cultures, ages, and experiences in order to develop a more comprehensive understanding of the true essence of parenting a child with autism.

As well, the study does not directly address the impact of influence from extended families. The inter-familial relationships with extended family members may also have offered valuable insight on the implications of parenting a child with autism.

### Implications of the Study

The major implications of the study's findings primarily relate to parents and caregivers of children with autism but may also have resounding associations for the educators of these children. The evolving themes and the recommendations of the participants have implications that may positively affect the experience of parenting as well as educating a child with autism. The first implication applies to the parent-educator relationship and the necessity of regular communication. The data from the current study also indicate that parents offer a wealth of information with regards to their child's needs. Therefore, if future teachers are aware that specific strategies will be conducive to the

child's learning environment, they may benefit from the parent's insight. Finally, educators and administrators need to be aware that teachers who instruct a child with autism may also experience many of the stresses associated with the child's needs. With additional information relating to autism, future educators will be better equipped to understand the needs of families affected by autism.

### Extensions for Research

Research has not adequately investigated the subject of resilience and autism. During the process of inquiry, numerous topics worthy of future research into this subject area surfaced. Further exploration of sibling development and behavioural manifestations due to having a brother or sister with autism would be a subject worthy of additional review. A longitudinal study of marital success rates in families affected by autism and the value of community support groups are among the thoughts evoked from this study.

It is important to note that, unlike quantitative research, that strives to generalize findings from a sample to a defined population, qualitative research strives to represent findings that have similar cases of the phenomena (Anderson & Arsenault, 1998). Therefore, the results of this study sought to raise awareness of what is like to have a child with autism rather than to generalize findings to the greater population. A quantitative study to examine results consistent across numerous participants from different demographics or with various socioeconomic groups would offer a more thorough research project. Perhaps a longitudinal study design could enhance the long-term implications of a family affected by autism. A longitudinal study might also help to clarify the development and success of social supports over time.

Future research could be conducted to discover if the attributes and characteristics conducive to healthy adaptation such as self-efficacy, determination, flexibility and adaptability could be taught to individuals to improve their success in parenting a child with autism. It may be constructive to have a more intense strategy to teach families the skills of advocacy, problem solving and positive outlook and how to maintain these.

Consistent with many research projects, this study creates as much inquiry as it resolves. Research is carried out not to confirm or disconfirm earlier findings, but rather to contribute to a process of continuous review and enhancement of understanding of the experience (Lincoln & Guba, 1985).

## Conclusion

This qualitative study employed a phenomenological approach to explore the experiences of a family affected by autism. As indicated in the data from the theme adversity and stress, the participants in the current study live with the hardships and adversity of raising a child with autism and have emerged from their adversity with dignity and strength. This study has shed some light on the issues and trials faced by the family of participants and the ways in which they managed to overcome the challenges of parenting a child with autism. For example, these strategies surfaced from the themes of: adaptability and flexibility and support from family or community. The contributing factors, attributes and characteristics that have helped them emerge with dignity, strength and resilience have been explored in the themes of: acceptance and understanding, self-efficacy, strength and determination. This study sought to identify the elements that enabled the participants to emerge from their daily trials with a healthy adaptation. The rich description of the themes has contributed to the understanding of a family affected

by autism, providing experiential evidence of successful strategies to mitigate the impact of a child's autism.

Phenomenology serves as the rationale behind efforts to understand individuals by entering into their field of perception in order to see life as these individuals see it (Creswell, 1998). The study enhances our knowledge and perception of the qualities and attributes which assist in the resilient adaptation of this family affected by autism. Their model of resilience helps us to understand why they emerged from adversity and prevailed despite many obstacles.

The findings of this study enhance the essence of the lived experience of the family of a child with autism for the reader. Essential information has been gleaned from the participants during their interviews. The essence of understanding the lived experiences of the participants has been summed up in the following: maintaining an optimism and belief in themselves and in their child, accessing supports, drawing upon an inner strength and fortitude, celebrating joys and successes, acceptance and unconditional love for all members of the family have all contributed to the emerging resilience in the family of participants. While these themes augment the current literature, they also add rich qualitative descriptions to further understanding. This phenomenological study has provided a vivid insight into the personal lives of a family affected by autism.

In closing, the results of this study have been promising and suggest that advantageous outcomes can be enhanced by improving problem-solving skills, coping strategies and remaining adaptive. As anticipated, the qualities that prepared the participants to be exemplary models of how to parent in a family affected by autism did emerge. The participants have proven to have unique strengths and gifts that enable them

to achieve their high level of resilience. Understanding what these attributes and characteristics are may enable professionals to be more compassionate and may assist them to enhance their support for families caring for children with autism.

The purpose of this study has been to analyze the emerging resilience in a family affected by autism. This phenomenological study has drawn conclusions about the participants and discovered the qualities and distinctive characteristics that contribute to their healthy adaptation of having a child with autism. Throughout this research project, the question often asked by friends and family was, “What is autism?” Thomas Whitman (2004) enlightens us with this description: autism does not exist in its own right, “there are only people with autism” (Whitman, 2004, p.139).

Heiman (2002) proposes that it is a great societal benefit to recognize and learn from the resilience, strength and positive relationships among the family members of children with special needs. In this respect, the participants have been exemplary models for our discovery. Their candor, incisive interpretations, keen understanding, and astute recommendations have guided the perception and understanding of the researcher and reader alike. Their story has been told with the intention of our greater empathy of the life of a family affected by autism and for this the participants are owed an immeasurable debt of gratitude. The participants of this study are unsung heroes of the ever-complex endeavor of parenting a child with autism.



## Appendix A: Diagnostic Criteria

The following information is provided from the Diagnostic and Statistical Manual of mental Disorders, Fourth Edition (DSM IV):

### Diagnostic Criteria for 299.00 Autistic Disorder

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3)
  - (1) Qualitative impairment in social interaction, as manifested by at least two of the following:
    - a) Marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
    - b) Failure to develop peer relationships appropriate to developmental level
    - c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
    - d) Lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids)
  - (2) Qualitative impairments in communication as manifested by at least one of the following:
    - a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
    - b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
    - c) Stereotyped and repetitive use of language or idiosyncratic language
    - d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
  - (3) Restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least two of the following:
    - a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    - b) Apparently inflexible adherence to specific, nonfunctional routines or rituals
    - c) Stereotyped and repetitive motor mannerisms (e.g hand or finger flapping or twisting, or complex whole-body movements)
    - d) Persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:
  - (1) Social interaction
  - (2) Language as used in social communication
  - (3) Symbolic or imaginative play
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

## Appendix B: Ethics Documentation

### **Information Letter and Consent Form**

#### **DEAR PARENTS,**

You and your children are invited to participate in a study entitled: *Emerging Resilience in a Family Affected by Autism*. Due to the fact that I have previously taught your children and in doing so have also come to know you both, I need to advise you that although we have this prior relationship you should feel no pressure to participate in this study. Please do not feel compelled to participate. Your participation is voluntary. You will receive no personal benefit for participating.

Please read this form carefully, and feel free to ask questions you might have.

If interested in participating in the study, we would ask you to each complete the form and return them to Lori Mierau in the self addressed attached envelope at your earliest convenience. At this time, you are the only family that has been selected to participate in this study.

#### **Researcher(s):**

Ms. Lori Mierau, Special Education Masters Student, College of Education, University of Saskatchewan.

426 Elm St. Saskatoon, SK

Ph: 477-7418

Email: mieraull@spsd.sk.ca

#### **Research Advisor:**

Dr. David Mykota Professor, Department of Educational Psychology and Special Education, College of Education, University of Saskatchewan.

Ph: 966-5258

Email: david.mykota@usask.ca

#### **Purpose and Procedure:**

The purpose of this phenomenological study is to research the dynamics of a family who displays a healthy adaptation with reference to all of the stressors associated with a diagnosis of autism. Phenomenology is the study of structures as experienced from the first person point of view (Bogdan & Biklen, 2003). The intent is to understand and describe an event from the point of view of the participant. The rationale for this phenomenological study follows from a need for increased understanding in the phenomenon of resilience in families affected by autism. This phenomenological study will research the attributes and characteristics that contribute to the healthy adaptation of the family.

#### **A brief outline of the activities:**

The procedure of gathering the information from the family will be conducted in a series of interviews with the parents, and one interview with the son with autism and his sister. The participants will be instructed to answer the interview questions that they approve of with honesty and accuracy. The parents will be required to sign off their transcriptions and the transcriptions of their children so that any appropriate changes can be made before final written conclusions will be produced.

There will be a series of three potential parental interviews. The first will take approximately fifteen minutes, the second will take approximately thirty to forty-five minutes, and the third interview will take place only if clarification is necessary as a result of the first two interviews. There will be only one interview with the children and will take approximately fifteen to twenty minutes. At least one parent will be present for the interviews of the children. The interviews will all take place in the family's home. Interviews will be audio taped and later transcribed. The participants may ask to have the tape recorder shut off at any point during the interview process. After the interview and prior to the data being included in the final report, the parents will be given the opportunity to review the transcript of their own interview as well as their children's interviews to add, alter, or delete information from the transcripts as they see fit.

At the end of the interviewing process, the family will be provided with a list of support agencies and their contact numbers in the event that issues are raised during the process of the interviews that family members would like to seek help with. Any family members may choose to decline from answering any of the questions or activities that they are not comfortable with and can withdraw from the study for any reason and at any time. The decision to withdraw will not affect the family's access to any services. If a family member chooses to withdraw from the study, his/her data will be deleted from the study and destroyed. The parent participants will be debriefed upon completion of the interview [See Appendix H-Debriefing Statement].

The confidentiality of the family will be respected. Although the data from this study will be published and may be presented at conferences, the data will be prepared using pseudonyms with the written form. Consent forms will be stored separately from the interview transcripts. The data from the study will be stored in a locked cabinet in the Department of Educational Psychology and Special Education, College of Education, University of Saskatchewan for a minimum of five years.

The data collected will be analyzed and the written conclusions will be reported once the transcriptions have been approved. The final written product will be presented in a thesis entitled: *Emerging Resilience in a Family Affected by Autism*.

Total interviewing time will be approximately one hour for each of the parents and approximately twenty minutes for each of the children.

**Potential Risks:**

There are minimal risks involved in participation in this study including limited time taken away from their personal activities for the interviews, and the possibility that over

the course of the interviews concerns will be vocalized by various family members that were not previously discussed within the family unit. To minimize the impact of the time commitment, the number of interview questions for the parents was restricted to six for the first interview, eleven for the second interview (the questions for the third interview will be devised after the first two interviews if clarification is necessary). The interview questions for the children was restricted to four.

The researcher acknowledges that there is also the potential for a certain amount of discomfort for the participants with regards to the personal nature of the interview questions. In anticipation of potential issues being raised during the course of the interviews, a number of agencies with their contact information will be provided to the parents at the end of the interview process.

### **Potential Benefits:**

The possible benefit of the study is to gain an understanding of what it is like to have a child with autism as a family member. Qualitative, phenomenological research excels at bringing us to an understanding of complex issues that can expand the experience or add power to the knowledge that has been acquired through prior research (Brown, 2006). Qualitative, phenomenological research emphasizes detailed contextual analysis of a limited number of events or conditions and their relationships. It is within this framework that the researcher will gain valuable insights into the process of the acceptance of the diagnosis of autism for this family.

### **Storage of Data:**

L. Mierau and Dr. Mykota will store all data associated with this study in a secured location accessible only to these researchers. In addition, to further assure confidentiality, all data will be identified by use of pseudonyms and the actual names of the participants will be kept in a separate, secured location accessible only to these researchers at the U of S. All data will be stored for a period of five years after the completion of the study after which all data will be destroyed.

### **Confidentiality:**

The researcher will undertake to safeguard the confidentiality of the participants by utilizing pseudonyms and maintaining researcher confidentiality, but cannot guarantee that others who read the thesis will not be able to identify the members of the group.

Consent forms will be stored separately from the interview transcripts. The data from the study will be stored in a locked cabinet in the Department of Educational Psychology and Special Education, College of Education, University of Saskatchewan for a minimum of five years.

The data collected will be analyzed and the written conclusions will be reported once the transcripts have been approved. The final written product will be presented in a thesis entitled: *Emerging Resilience in a Family Affected by Autism*.

The participants will be given the phone number of the researcher, the advisor and the ethics department of the University of Saskatchewan. Researcher, Lori Mierau, department of Special Education, College of Education, Master's Program, 306-477-7418. Research advisor is Dr. David Mykota, University of Saskatchewan, 306-966-5258. Phone number for the Ethics office, 306-966-2084.

**Right to Withdraw:** Each participant's contribution is voluntary, and he/she may withdraw from the study for any reason, at any time, without penalty of any sort. Any data collected will be destroyed at his/her request.

**Questions:** If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the research advisor at the number provided above if you have questions at a later time. The University of Saskatchewan Behavioural Research Ethics Board has approved this study on ethical grounds on (insert date). Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (966-2084).

The results of the study may be shared both in the written form and by a verbal presentation with other professionals.

**Consent to Participate:** I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. **I consent** to participate in the study described above, understanding that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.

---

(Name of Participant)

---

(Date)

---

(Signature of Participant/parent)

---

(Signature of Researcher)

**Decline to Participate:** I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. **I DO NOT consent** to participate in the study described above.

---

(Name of Participant)

---

(Date)

---

(Signature of Participant/parent)

---

(Signature of Researcher)

## Child Assent Form

Dear Children,

You have been invited to participate in a research study and interview process with researcher, Lori Mierau. I would like to find out some information about what it is like to be a part of your family. I would like to ask you some questions about what you enjoy doing together and about what it is like to be a part of your family.

Please feel free to ask me any questions about the study and the interview process. If you do not understand the questions in the interview you can ask me for help. You can answer only the questions that you feel comfortable with.

If you would like to participate with this study please sign your name at the bottom of this form.

**Assent to participate:** I understand that I will be interviewed for a research project and I would like to **consent** participate in this study.

---

(Name of Participant)

---

(Date)

---

(Signature of parent)

---

(Signature of Researcher)

**Decline to participate:** I understand the process of the research study and I would like to **decline** from participating in this research project.

---

(Name of Participant)

---

(Date)

---

(Signature of parent)

---

(Signature of Researcher)

## Appendix C: Interview Questions

### Parent First Interview Questions:

1. When and why did you first suspect that your child was not developing typically?
2. How many specialists or professionals can you estimate that were involved with making the diagnosis?
3. To your knowledge, is there any paternal/maternal family history of autism?
4. How old was your child when he first began to use expressive language?
5. What school modifications and accommodations have been necessary for your child?
6. Has your child's diagnosis impacted or limited the size of your family?

### Parent Second Interview Questions:

1. How did you respond or react when you first heard the diagnosis of autism?
2. Can you describe your feelings about your daily involvements, related to having a child with a diagnosis of autism? For example, please illustrate the challenges of a typical daily event and the strategies that you might utilize to create a harmony for this routine.
3. How does your child's diagnosis affect your family life, and how do you cope with these challenges?
4. Can you illustrate the impact of having a child with autism on inter-family relationships? For example how do you, as a parent, ensure that the needs of the individual family members are met?
5. What are your thoughts on the inclusive classroom?
6. Can you describe your child's relationships with his peers within and outside of school?
7. What are your thoughts on how teachers can facilitate positive peer interactions among all students in our classrooms?

8. Can you explain the transitioning aspects and challenges of your child's school experience and what modifications you make to facilitate a smooth transition? For example, the beginning of a school year, new seasons & holidays and a replacement/substitute teacher.
9. What are your hopes and dreams for your child?
10. Please describe your characteristics or strengths that you feel have attributed to your success in parenting both of your children.
11. If you could talk to other parents with autism, what suggestions would you have for them?

#### Parent Third Interview Questions:

1. You mention in your second interview that your first reaction to your son's diagnosis of autism resulted in disappointment, disbelief and resentment. Can you elaborate on this sense of loss? What specifically did you resent?
2. You refer to flexibility and routine as beneficial for your son. Can you describe an example of the adaptations or accommodations that are needed to ease through changes in routine?
3. Please list some examples of the positive steps that you and your family have taken to ensure your success in parenting a child with autism.
4. Can you describe the personal characteristics or strengths that you possess that have attributed to your success of raising Brayden?
5. Please describe the positive aspects of your relationship with your son.

#### Children First Interview Questions:

1. Tell me about your family.
2. What is your favorite thing to do with your brother/sister?
3. What is your favorite thing to do with your Mom?
4. What is your favorite thing to do with your Dad?



Children Second Interview Questions:

1. If you could talk to the most important person in the world and tell them about autism, what would you say?
2. What should your friends at school know about autism?
3. What do you tell your friends about your brother? For example are there rules that they should know about before they come to play at your house? (For the sibling only)
4. What should we teach other children so that they learn to work together with everyone, even children who are different?
5. At school or on the playground, if someone is bothering you what do you do? (For the child with autism)

## Appendix D: Support Services

1. Autism Treatment Services of Saskatoon. Phone: 665-7013 or on line: [www.health.gov.sk.ca/rr\\_autism.pdf](http://www.health.gov.sk.ca/rr_autism.pdf).
2. Alvin Buckwold Child Development Program, Saskatoon Health Region Autism Treatment Services of Saskatchewan. Phone: 655-1070 or on line: [www.saskatoonhealthregion.ca/your\\_health/ps\\_alvin\\_buckwold\\_autism.htm](http://www.saskatoonhealthregion.ca/your_health/ps_alvin_buckwold_autism.htm).
3. Autism Support Group providing Advocacy Awareness, Support, ... Autism Treatment Services of Saskatchewan, Inc. The Saskatoon Society for Autism, on line: [www.family-friendly-fun.com/family-disability-files/autismsociety.html](http://www.family-friendly-fun.com/family-disability-files/autismsociety.html).
4. Saskatchewan Family Services on line: [www.familyservice.sk.ca/links.html](http://www.familyservice.sk.ca/links.html).

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