

The Lived Experience of Parenting a Child with  
Autism in a Rural Area: Making the Invisible, Visible

by

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## Abstract

Derived from the Greek word “self,” autism, a neurological disorder where children seem to be enclosed in their own world, is becoming increasingly more prevalent today.

Although there is research detailing the challenges and stresses, coping strategies and lived experience faced by parents of children with autism, the majority of this work involves urban parents. Missing is research detailing the experience of rural parents.

Accordingly, a phenomenological study was conducted to arrive at an understanding of the lived experience of parents who are parenting a child with autism while living in a rural area. The philosophy of hermeneutic phenomenology was used to guide this qualitative inquiry. Audio-taped, in-depth interviews of 26 families served as primary data. Thematic statements were isolated using van Manen’s (1990) selective highlighting approach. In this approach, the search for themes or structures of the experience involved selecting and highlighting sentences or sentence clusters that stand out as thematic of the experience. Making the invisible, visible emerged as the essence of the parents’ experience. Parents shared that although autism is an invisible disease, they in fact made it visible in their constant battles to ensure that their child received the best quality of life within a community that supported and valued their child. This essence was represented by five themes: (1) using autism to enable; (2) lifelong advocating; (3) centering autism within the family; (4) the ups and downs of living rurally; and (4) a renewed sense of parenting. Findings from this study may be used to guide policy and program development that is concerned with supporting the development of children with autism and improving the health and quality of life of rural families of children with autism.

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### Dedication

This thesis is dedicated to all those families parenting a child with autism, especially to those 26 families who graciously accepted the invitation to participate and share their heartfelt stories.

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## Chapter I: Statement of the Problem

### Introduction

Derived from the Greek word “self,” autism, a neurological disorder where children seem to be enclosed in their own world, is becoming increasingly more prevalent today. Affecting boys three to four times more than girls (Beauchesne & Kelley, 2004; Behrman, Kliegman & Jenson, 2000), a once thought rare condition is now very common. Characterized by the impaired ability to engage in social interaction, impaired communication, restricted interests and repetitive behaviour, children diagnosed with autism are faced with an incapacitating life-long disability (Behrman et al. 2000; Committee on Children with Disabilities, 2001). The cause of autism is unknown. There has been some link to genetic factors and a variety of other theories of causation have been studied (Behrman et al., 2000). Autism is a disorder that develops before the age of 30 months, and is a disability that occurs throughout the life of the child. Despite the early onset, diagnosis is often delayed until or after late preschool years (Beauchesne & Kelley, 2004) or according to a study done by Howlin and Moore (1997), children were diagnosed with autism as late as 6 years of age.

Parenting a child with autism can be a challenging and frustrating experience. Children diagnosed with autism display poorly developed verbal and nonverbal communication; they have a lack of empathy and have difficulty maintaining eye contact. Children with autism have a strong need for sameness and may spend hours in solitary play. Ritualistic behaviour is often seen in children with autism, and disruption in any routine may lead to tantrums and meltdowns (Hockenberry & Wilson, 2007). Coupled with these challenges is the recommended intense treatment that incorporates a variety of

intervention strategies tailored to the individual developmental needs of the child and their family (Committee on Children with Disabilities, 2001). Although there is no cure for children with autism, the goal of treatment is to increase skill development in all areas and to decrease quantity and severity of unwanted behaviours (Bryson, Rogers, & Fombonne, 2003; Committee on Children with Disabilities, 2001).

Despite the ongoing and added responsibilities of caring for a child with autism, parents have reported positive experiences such as connecting with their child, achieving unique milestones, and developing patience (Cashin, 2004). Other parents have reported a change in world views and values concerning life and disability which is seen as a positive experience. Overall, parents realize that their child can make a positive contribution to themselves, their family, and their community (King, Zwaigenbaum, King, Baxter, Rosenbaum & Bates, 2006).

Although there is research detailing the stresses, challenges and opportunities, coping strategies, psychological functioning, and lived experience of what parents of children with autism face, the majority of this work involves urban parents. Few authors have researched the experience of families of children with disabilities who live in rural areas. In short, little is known about the rural experience. Furthermore, lacking is research that seeks to understand the unique experience of rural families parenting a child with autism specifically. To date, there has been no research on the parenting experience of rural parents of children with autism. In order to ensure that the concerns and needs of rural parents of children with autism are being adequately addressed, research detailing the experience of these rural parents was warranted. Obtaining this knowledge was best suited with a qualitative approach, particularly phenomenology.

### Purpose and Research Objectives

The central focus of phenomenology inquiry is to explore the lived experience of everyday life (Speziale & Carpenter, 2007). This study provides insight into how rural parents live, see, and interpret the daily life of parenting a child with autism. Hence, the purpose of this qualitative study was to explore the lived experience of parents in rural areas who were parenting a child with autism. The research questions addressed in this study include:

1. What characterizes the day-to-day-living for parents from rural areas who are parenting a child with autism?
2. What meanings do rural parents attribute to parenting a child with autism?
3. What recommendations do rural parents have about how professionals can best support families of children with autism?

In arriving at an understanding of what it was like to parent a child with autism, attention was given to understanding and describing the experience from that of the parent. In particular, how they participated in daily life, what quality of life was like for them, what their needs were, and what services were needed to meet their needs were explored.

### Definition of the Study's Major Constructs

For the purpose of this study, the major constructs were defined as the following:

*Parent(s)*: Parent or parents refer to any primary caregiver to the child with autism. This included biological parents, grandparents, foster parents or any other caregiver with whom a long-term or life-long commitment exists.

*Rural Area:* Rural area included all families living outside the perimeter of the City of Winnipeg.

*Meanings:* Meanings are lived and are referred to the way a person experiences and understands his or her world as real and meaningful (van Manen, 1990). Meanings attached to experiences and events are positive, negative or neutral, and changed as changes occur in situations and relations (Woodgate, 2001).

#### Assumptions and Preliminary Work

My experience as a paediatric nurse has provided me with the understanding of what it is like to care for families who have a child with a life-long disability. Nurses in a paediatric setting often provide care for many resilient children who get sick and recover but there are also those children faced with disabilities that affect them throughout their life span. Caring for these children can be stressful and many parents face challenges, difficulties and frustrations. Fortunately, my experiences have shown that these families often see the joy in the small hurdles they overcome. Parents are taught new skills that are far beyond the scope of any parenting class. They must adapt to the special needs of their child and constantly advocate on their child's behalf. Parents are thrown into a world of putting their own needs behind those of their disabled child's. They transition through novice learners to experts in the realm of their child's health. Caring for a disabled child is a continuous process where parents are primary caregivers and as nurses, we must equip them with the skills and resources to be able to provide the best quality of life for their child.

While working in an isolated town with one paediatric floor in a larger adult hospital, there were many families that came from smaller rural areas. These families

were often faced with limited resources and supplies, as well as, a lack of support and services. When a child becomes sick or is faced with a disability, families in rural communities are forced to leave their home, come to a larger, new town and seek the medical treatment and services that are unavailable to them. Nurses that care for families that come from rural areas are faced with unique challenges that are quite different than those families in an urban setting. Discharge from the hospital is a complex time for these children and their family. As a nurse, it is important to make sure that parents have the support they need and that parents' needs are fulfilled. Discharging a child with a disability or health condition to a rural area becomes difficult for nurses as there is a lack of supplies, resources, and appropriate follow-up. Many families are required to stay within the city for a certain period after being discharged while other families must return to the city at a later time for follow up appointments. Families are faced with the added costs of travelling and living expenses while being away with their child. Families with siblings must arrange child care and in a time of financial strain many parents are required to change or quit their job to care for their child.

Children with autism are a unique population. Although children with autism tend not to have a great deal of admissions into the hospital, the recommended treatment is intense requiring total commitment from parents. Children with autism are very individualistic and caring for these children takes on a unique approach as no standard method will be successful for every child. While completing my practicum experience in the Master of Nursing program, I had the opportunity to interact with families who were faced with a newly diagnosed child with autism and families that were engaged in an intense behaviour modification program. Children with autism and their families require

immense support throughout their lifetime. With the combined added challenge of living in a rural area, these families have the odds against them. After attending a presentation on the experience of parents parenting a child with autism while living in an urban setting, it became quite apparent that there was a need to explore the lives of rural parents. It is my belief that by enhancing our understanding of the lived experience of families parenting a child with autism, it will assist nurses and other health care professionals whether in the community or within a health care setting in their ability to provide ongoing comprehensive care and support to these families.

In a research study, it is important to be explicit about any underlying assumptions. Assumptions for this research study were based upon the philosophical beliefs and characteristics of qualitative research through the philosophical framework of van Manen (Speziale & Carpenter, 2007; van Manen, 1990). In this study, the underlying assumptions were: (a) phenomena are understood in different ways due to the multiple realities that exist and create unique meanings for individuals, (b) the researcher interacts with the participants in the inquiry to obtain data which adds to the richness of the collected data, and (c) parents of children with autism living in a rural area are the experts in describing their experience of parenting their child and exploring their world.

#### Significance of the Study

Parenting was expressed as both rewarding and challenging. Parenting a child with autism was a unique experience and living in a rural area added its own distinct difficulties. Treatment was intense and total family involvement was vital. Advocating for these parents is imperative to overall improve the quality of life of a child with autism. Hearing from individual parents will help parents of children with autism learn

specific strategies, give hope for the future, and improve their child's quality of life.

Overall, this study resulted in new insights into the lives of rural parents of children with autism. Findings from this study may be used to guide policy and program development that is concerned with supporting the development of children with autism, as well as, improve the health and quality of life of parents of children with autism. Findings will also help parents understand that they are not alone in this lifelong journey of autism.

### Chapter Summary

Chapter one provided an overview of the rationale for researching families with a child with autism who live in a rural area. As there was no published literature exploring the nature of rural families parenting a child with autism, research in this area was greatly warranted. Moreover, there is a limited amount of published research examining the lived experience of parenting a child with autism. Furthermore, the prevalence of autism is on the rise and studies that delve into the lived experience only serve to benefit health care professionals, other families facing similar situations, and overall, provide a greater understanding in enhancing the quality of life for families parenting a child with autism. Following chapter one, chapter two will explore the literature and present the groundwork underpinning this research.

## Chapter II: Literature Review

### Introduction

Chapter two reviews the literature that created the concrete foundation to explore the experience of rural parents parenting a child with autism. This section provides an in-depth review of the literature of parenting a child with autism, caring for a child with disabilities, and relevant literature based on rural experiences. A brief outline of autism is provided, followed by an overview of parenting a child with disabilities. Pertinent literature on rural families' experiences is discussed with the final section looking specifically at parenting a child with autism.

### *Defining Autism*

With a prevalence of 10 in 10,000 (Fombonne, 2003), autism, a once thought severe and rare condition is now commonly recognized within the health care sector. Characterized by a triad of impairments, children with autism typically display an impaired ability to engage in social interaction, have atypical communication skills, and engage in repetitive, restricted, and unusual behaviour (Behrman et al., 2000; Caronna, Milunsky, & Tager-Flusberg, 2008). Although there has been a heightened awareness in autism with a surge of intense research into the subject and related conditions, there are still many unanswered questions and unknowns that remain. Despite the rigorous and concentrated research specifically on the cause of autism and autism spectrum disorders the cause still remains unclear (Behrman et al.; Caronna et al.). As the prevalence of autism appears to be on the rise (Caronna et al.), the quality and quantity of research has risen dramatically over the past decade. From the belief that early detection and intense treatment can significantly improve the quality of life for children with autism, to



improved diagnostic tools and instruments, physicians are now able to reliably diagnose a child with autism by age two (Moore & Goodson, 2003).

Showing to be developed by 30 months, a delay or abnormality in verbal language development is the most common concern brought up by parents (Howlin & Moore, 1997). Over 40% of the parents in a study by Howlin and Moore stated that a delay in communication skills was their primary concern that something was not right with their child. Although rare, occasionally some children with autism display savant-like characteristics, excelling in one talent. The majority of children with autism display deficits in cognitive processing which becomes most apparent in emotional situations, and a wide variation of developmental delays is seen with children diagnosed with autism (Caronna et al., 2008). Children with autism may display hand flapping or twisting, intense preoccupation with parts of an object and extreme inflexible adherence to any type of routine or ritual (Hockenberry & Wilson, 2007). Overall, autism is a neurobehavioural condition that is believed “to have diverse etiologies and is defined by the presence or absence of a constellation of symptoms” (Committee on Children with Disabilities, 2001).

To diagnosis a child with autism a comprehensive evaluation by a physician needs to occur. After obtaining a thorough developmental history including parental concerns, communication behaviours, tantrum frequency, and eating/sleeping disturbances, chromosomal studies are recommended to rule out other neurodevelopment disorders such as Fragile X Syndrome, Angelmon Syndrome, and Smith-Lemlil-Opitz Syndrome. Other testing such as metabolic, neuro-imaging and sleep deprived electroencephalography are ordered if the symptoms warrant further evaluation

(Augustyn, 2008; Committee on Children with Disabilities, 2001; Caronna et al., 2008). Ancillary testing including vision and hearing, speech language and communication, developmental and intelligence testing are deemed necessary to rule out other underlying conditions. Although the DSM-IV-TR clearly outlines the criteria for a diagnosis of autism, there are multiple diagnostic tools that are available to aid clinicians. Tools such as the Autism Behaviour Checklist and Gilliam Autism Rating Scale require the parents' participation in filling out a checklist while the Childhood Autism Rating Scale, the Autism Diagnostic Observation Schedule-Generic, and the Checklist for Autism in Children require an interviewer and/or observational time by a clinician (Augustyn; Bryson et al., 2003). Unfortunately, although these tools have been developed to assist physicians in detecting and diagnosing autism, additional validation to assess their reliability and specificity across variable populations is warranted (Committee on Children with Disabilities, 2001).

Beginning in the late 1980's, comprehensive early intervention programs were developed using highly focused and individualistic teaching methods that take place over many hours throughout the week (Bryson et al., 2003). Although it has been recently concluded that there is no one single best approach for a child with autism or even for a child across their lifespan, an early intense behaviour therapy also referred to as Applied Behaviour Analysis (ABA) or Early Individualized Behavioural Intervention (EIBI) is a treatment option for children with autism that continues to warrant further study (Bryson et al.; Volkmar, Lord, Bailey, Sctultz & Klin, 2004). Furthermore, other treatment models found in the literature include the Relationship Development Intervention (RDI) model (Gutstein, Burgess & Montfort, 2007), Dr. Greenspan's Development, Individual

Difference, and Relationship-Based (DIR) Floortime model, and complementary/alternative medicine options including music therapy, yeast free or gluten/casein free diets, and dietary supplements.

In regards to autism, treatment has been found to be most successful when it is variable, begins as early as possible, incorporates parent training and support, and changes over the course of the child's life to best suit his or her needs (Behrman et al., 2000; Meyers, Johnson & the Council on Children with Disabilities, 2007).

Developed by Lovaas in the early 1970's, ABA is a behavioural-intervention treatment aimed at motivating the child to be successful (Lovass, 1987). ABA strives to organize therapeutic experiences that lead to enduring positive changes over time and across settings in areas such as toileting, feeding, social skills, and language (Foxy, 2008; Lovass). ABA requires intense one-on-one interaction by a specifically trained tutor for 31 hours a week. Skills are broken down into smaller components and as the child progresses, the complexity increases. Positive reinforcement is utilized, and children are followed by a senior tutor as well as, an ABA Consultant.

DIR Floortime is a model developed for the treatment of autism by Dr. Stanley Greenspan (Wieder & Greenspan, 2003). DIR Floortime incorporates play and is designed as a systematic way of working with children to help them climb the developmental ladder (Greenspan & Wieder, 2008). With an objective of building health foundations for social, emotional, and intellectual capacities rather than a focus on skills and isolated behaviours, the DIR Floortime model requires parents to get down on the floor to play and interact with their child for 20-30 minutes, 6-8 times a day (Greenspan,

2006). DIR Floortime incorporates a team approach including speech, occupational and physical therapies, educational programs, and mental health services (Greenspan).

A third treatment model is RDI, and this model focuses on activities that encourage interactive behaviours with the goal of engaging the child in social relationships so that the child becomes motivated to learn further skills necessary to retain relationships (Gutstein et al., 2007). The day to day interaction requires parents to work with their child and videotape sessions for review by the consultant. Parents take an extensive workshop on the theory, principles and components of RDI and have regular biweekly consultation meetings with a certified RDI consultant (Gutstein et al.).

Overall, autism is an extremely complex disorder, and every intervention program must be specific to that child. Staff must be properly trained to use evidence-based methods for teaching and dealing with behavioural issues. The emotional and social well being of the child must be consistently dealt with throughout the child's life to enable participants and a better quality of life. Family involvement is significant in achieving the best possible outcome for the child. Providing a well structured environment is crucial in managing children with autism, while promoting positive reinforcement, heightening the awareness of others around them, increasing verbal communication skills, and decreasing unwanted and unacceptable behaviours are fundamental objectives of any treatment (Hockenberry & Wilson, 2007). Prognosis of a child with autism is highly individualized. A better prognosis is seen in children that are higher functioning, have verbal communication, have less stereotypical behaviour and have lesser symptoms at the time of diagnosis (Behrman et al., 2000). Early detection and intervention is significant in minimizing the associated disabilities that affect children with autism. Although there are

considerable advances and prognosis in the field of autism, further research is still warranted. Prospective studies of high-risk populations and research on improved methods of early diagnosis would be beneficial. Furthermore, although the area on treatment has grown tremendously, there still is a great need for research to be done on the validation of each strategy and method. It is also imperative to research what treatment model parents' use, what is deemed to be effective or non-effective and the best way to integrate these practices into the school system to effectively improve the lives of children with autism (Volkmar et al., 2004).

### *Parenting a Child with a Disability*

Autism is a disability, and parenting a child with a disability is entirely unique. To provide a thorough literature review, it is imperative to include what has been researched on children with disabilities and the distinctive acquired parenting skills. This section explores the nature of parenting a child with disabilities. In Canada, one in eight Canadians has a disability and approximately 180,000 children ages 0 to 14 are disabled (Statistics Canada, 2004). Disabilities of these children range from chronic health conditions to developmental delays to learning disabilities. Of all children aged 0 to 4, 2% are affected by a disability and this rate doubles to 4% when the age group changes to children aged 5 to 14 (Statistics Canada). As well, at least 25% of school-aged children require help with bathing, grooming and other activities of daily living, and families of disabled children have lower household income than those that do not have a disabled child (Statistics Canada). Statistically in Canada, 15% of all disabled children that need specialized equipment do not have access to receive this equipment and 65% of families

do not get all the help that they require to care for their child with disabilities (Statistics Canada).

Caring for a child with a disability is a life-long commitment and requires great time and resources from the family. Parenting a child with a disability is often challenging and frustrating, but yet rewarding. Families must learn to cope and adapt with the everyday activities that require physical, emotional, social, and financial resources that are not always available. In addition to having to care 24 hours a day for their child, parents must coordinate the numerous medical appointments and developmental interventions while balancing the needs of the rest of the family. Much of the research in the literature, focuses on mothers and their complex, multi-facet role as primary caregiver to their disabled child. This is consistent with the statistic that 62% of mothers provide most of the personal care for disabled children compared to only three percent of the cases that involved father as primary caregiver (Statistics Canada, 2004). Research has focused on the experiences of parenting a child with special health care needs, attachment between the child and parents, health issues regarding parenting a special needs child and issues around employment. Six major themes are extracted from the literature regarding parenting a child with disabilities: (a) increased stress and burden, (b) focus on the child's health, (c) lack of support, (d) continuously advocating, (e) concern for the future, and (f) joys/life changing experience.

#### *Increased Stress and Burden*

It is well documented in the literature that, parenting a child with disabilities places increased stress and strain on a family. Studies by Durate, Bordin, Yazigi and Mooney (2005) and Schieve, Blumberg, Rice, Visser and Boyle (2007) have shown a

direct link between stress and parenting a child with autism. Ryan and Runswick-Cole (2008) looked specifically into the role of the mother of a disabled child and its ever-changing portrayal in society. These authors found that mothers took a medical standpoint of dealing with the stress and burden of taking care of their disabled child. There was a search for diagnosis and mothers went through a process that often ended in a no-win situation. Occurring over time was a shift from mother-blame to brain-blame. The authors concluded that mothering a child with a disability was fundamentally different than mothering a non-disabled child. Overall, mothering a child with disabilities was seen as a journey without a road map and a life full of adjustments and adaptations. Moreover, Mackey and Goddard (2006) conducted an interpretive research study looking at the health and wellness of mothers with children with intellectual disabilities and found that there was an increase in physical and mental work when parenting a child with disabilities. Murphy, Christian, Caplin, and Young (2006) conducted a research study with 40 parents and caregivers of children living with disabilities in urban, suburban and rural regions. Through questionnaires and focus groups, the authors concluded that parenting a child with disabilities was deemed extremely stressful on all caregivers. This was similar to the findings by Dellve, Samuelsson, Tallborn, Fasth, and Hallberg (2006) who reported that there was a high level of stress, physical and emotional strain among mothers of children with special needs.

In another study, Brehaut et al. (2004) explored the health and well-being of caregivers of children with cerebral palsy. Taking place in Ontario, Canada, 468 families of children with cerebral palsy were recruited into this study. The authors found that an increase in behavioural problems by the child showed a decrease in parental

psychological and physical health, whereas if the child had fewer behavioural problems the parent reported a greater ability to manage stress. Caregivers of a child with cerebral palsy reported more emotional, cognitive and physical health problems than parents in the control group. There was also a strong connection between parents in the study group and stress related conditions such as migraine headaches and ulcers. Similar results were found by King, King, Rosenbaum and Goffin (1999) in that the greater the child's behavioural problems, the greater amount of distress and depression found in parents. Overall, it is well documented in the literature that there is an increase in stress related to parenting a child with disabilities. Unique to the literature and pertinent to this study was that when parenting a child with disabilities, it was those children with behavioural problems that correlated to a greater stress in parents and caregivers than simply children with a disability.

#### *Focus on the Child's Health*

In parenting a child with disabilities, the focus for parents is on taking care of the needs of their child rather than taking care of their own needs and health. When looking at the health and wellness of mothers, Mackey and Goddard (2006) found that due to the increased work that was needed to take care of a child with intellectual disabilities, there was a significant focus on the child's health rather than their own. Not having enough sleep during the night and not being able to take naps during the afternoon led mothers to be consistently tired. Moreover, constant vigilance towards their child prevented mothers to look at and care for their own health. Overall, "the health of mothers of young children with developmental disabilities was background in time, space and the body, because their horizon of awareness, their foreground, was directed toward the health and needs of



their child with the disability” (Mackey & Goddard, 2006, p. 311). Additionally, Murphy et al. (2006) found that there was an overall negative impact on caregiver health of the 40 participating parents. Over half of the participants believed that their physical and emotional health had been negatively impacted by the demands of caring for a child with a disability. Lack of time, lack of available care providers, and the low priority of parents’ own health needs were identified as the barriers to addressing parents own needs; parents simply placed their child’s needs before their own.

In another study, MacDonald and Callery (2007) researched the experience of caring for a child with disabilities throughout the child’s lifespan. Through an ethnographic approach the authors interviewed mothers, fathers, nurses and social workers to enable a thorough understanding of the experience. During infancy, help and support was available as family and friends felt comfortable in caring for an infant. At this stage, intervention was not usually offered but should be considered to prevent a crisis further on. As the child aged, the more apparent the disability becomes. During the school-age era, “parents experienced fatigue, depression, boredom, isolation and an inability to work outside the home” (p. 211). Brandon (2007) found that compared to mothers of a non-disabled child, mothers parenting a child with disabilities spend four hour less per week on personal care. As well, mothers of a child with disabilities had less time per week available for socializing. Thyen, Kuhlthau, and Perrin (1999), found that over one third of participating mothers with a child assisted by technology had to quit their job to care for their child at home. Unfortunately, these mothers who were quitting their jobs were actually going through a time of increased financial need and therefore, the decision to quit or change jobs became that much harder. In addition, the authors

found that families caring for a child assisted by technology also had significantly less family support than parents of children without special needs. Findings of the Thyen et al. study also indicated that just under half of the mothers that worked stated that they had to work fewer hours, earned less pay and some even had to change jobs to continue to care for their child. This cross-sectional study by Thyen et al. included both a study and control group and strongly suggested that the families caring for a child with special needs were provided with social and financial supportive services. Overall, caregiver health is negatively impacted by caring for a child with a disability. Additionally, the literature identifies significant barriers to attending to caregivers' own health. Moreover, concern is warranted as worsening caregiver health may negatively impact the long-term needs of a child with a disability. Many caregivers, particularly mothers, put their own needs and health behind those of their family, especially when caring for a child with disabilities.

#### *Constantly Advocating*

Multiple studies have found that parents of children with disabilities must constantly advocate for their child. In a study by Ryan and Runswick-Cole (2008), the authors described the role of mothers through the eyes of the disabled child. Mothers were seen as allies, in whom they advocated for their child. These mothers had to acquire a whole new set of skills, they learned to negotiate, advocate, and mediate on behalf of their child. Furthermore, they created a "new" normal within their family life. As well, Lauver (2008) conducted a qualitative study on foster parents of children with chronic illness and found that just like biological parents (Murphy et al. 2006) foster parents took on an advocating role and learned how to provide care for their child's disability. Foster

parents learned how to listen to their own intuition, perform activities of daily living, and how to react and respond to slight changes in their child's behaviour. Lutenbacher, Karp, Ajero, Howe, and Williams (2005) echoed the need for parents to advocate for their child with special health care needs and how parents as well, became the expert in their child's condition. Overall, caregivers are constantly learning how to parent the ever-changing needs of their child with disabilities, and in order to provide the best care possible, parents learn to advocate for the needs of their child.

### *Lack of Support*

The lack of social, emotional and physical support when caring for a child with disabilities is well documented within the literature. Lutenbacher et al. (2005) looked at the challenges facing families caring for a child with special needs. Through the use of four focus groups, the authors found that there was an overall lack of support felt by participating families. Furthermore, frustrations were felt with the health care system and the lack of communication and collaboration between health, school and social services. Another area of concern for parents was the lack of knowledge that parents had received in regards to their child's condition. Difficulties with denied services, waiting periods and increased costs were further stresses brought up by the participants. Although the authors employed strategies to enhance validity and credibility, the ability to transfer findings to the greater population was limited.

“Being on their own” was the second identified theme in Mackey and Goddard's (2006) study on mothers parenting a child with disabilities. Although majority reported some family support, these participants still felt alone while caring for their child. Participating mothers felt that although they were alone, they had no other choice other

than to cope and survive. This is similar Murphy et al.'s (2006) study where parents described a lack of ability to share the burden. Majority of the caregivers provided all the care and described a lack of support while stressing the need for increased trained professionals who knew how to care for their child with complex needs. In another study, Lauver (2008) focused on the effectiveness of intervening strategies for parents parenting a child with disabilities. Echoing Murphy et al. and others (Hewitt-Taylor, 2005; Lutenbacher et al., 2005; MacDonald & Callery, 2007; Mackey & Goddard, 2006; Thyen et al., 1999) the inability to access needed health care services such as respite was an issue. In the infant to junior school stage of MacDonald and Callery's study, parents were found to have feelings of desperation, loss of self, and loss of future dreams. At this stage, homes often required increased medical equipment and became institutionalized. Family support was diminished and parents began to search for professional support in the form of respite care and services. Overall, lack of support, especially in the form of respite, lack of professionals and difficulties in accessing services were clear concerns felt by majority of the caregivers parenting a child with disabilities.

#### *Concerns for the Future*

Fear of the future is a significant concern found in the literature experienced by parents parenting a child with disabilities. MacDonald and Callery (2007) found that in the final transition from high school through young adulthood there was an intense increase in care giving and parents became increasingly worried about the future of their child. Moreover, at the age of 18, care services changed and this resulted in a gap in services for the child. Echoing this were the findings by Little and Clark (2006) and Murphy et al. (2006), in which they found that parents had great concern for their child's

future. Little and Clark described how the transition to adulthood and the possibility of independent living were of top concern of parents in their study. Furthermore, parents reported feelings of apprehension over their child's "social survival" wondering if their child will fit in or whether their child will fall into despair or depression. The authors established that negative fears of parents were related to independent living, finding a partner, concerns about the child being victimized by others and skill deficits by their child in areas such as reading, writing, and communicating. Although their sample was large, Little and Clark acknowledged that the participants were not drawn randomly as well as, it was limited to only those with internet access therefore, excluding families with fewer economic and educational resources.

In another study, Vickers and Parris (2005) found that mothers had great concern for the future of their child with special needs and MacDonald and Callery (2007) concluded that "early intervention and continuity would enable the professionals to work from knowledge of the full trajectory or care giving rather than from a given point in time" (p. 212). Overall, parental concerns regarding the future of their child with disabilities are documented in the literature.

#### *Joys and the Life Changing Experience*

When parenting a child with disabilities, few authors have acknowledged and explored the positive aspects and joys of parenting. In a study by Little and Clark (2006), the authors explored the experiences of parenting a child with Asperger's Syndrome and non-verbal learning disorder, with a specific focus on the joys and concerns of life with a disabled child. The authors felt that "only through a deeper understanding of family experiences can disability experts and other professionals develop, promote, and evaluate

intervention strategies aimed at improving the daily lives of these children and their families” (p. 40). Through the use of two surveys and 103 participants, three themes of joy were established. Enjoying the child’s unique characteristics and learning from the child while gaining personal insight and spending time together were the highlights of the positive parenting experience. In another study, Scorgie and Sobsey (2000) explored the significant and positive life changes in the lives of parents of children with disabilities. Through a two phase study, these authors found that there were many positive changes in parents’ lives that often go unpublished within the literature. Parents in the study by Scorgie and Sobsey believed that they were enriched by the new roles that they acquired while parenting a child with disabilities. Positive changes within themselves were seen as parents became more compassionate and less self-focused. Furthermore, family dynamics were altered which resulted in stronger marriages and moreover, parents described a change of what was important to them in their life. Similar to the study by Scorgie and Sobsey, Lauver (2008) found that fostering a fragile complex child was a life changing experience. Just like biological mothers, foster parents described both lifestyle and personal changes that occurred from parenting a child with special needs. In discussion, the authors found that it was through the day-today living experience of parenting a child with a disability where foster parents became the expert in their child’s care. From students, to novice learners, to advance caregivers, just like biological parents, foster parents faced similar unique challenges and joys when parenting a child with complex health care needs.

In conclusion, there is a tendency within the literature to group all disabled children together into one homogenous group. In reality, children with different

disabilities and different medical conditions have different needs, and the life experiences felt by each family is unique to each disability. It is argued “that the lumping together of such diverse experiences is, in itself, a form of disability, because it fails to engage with very different life experiences” (Ryan & Runswick-Cole, 2008, p. 207). This thought by Ryan and Runswick-Cole, was echoed by Reichman, Corman and Noonan (2008) who agreed that disabled children are a large heterogeneous group varying in age, diagnosis and severity, and family conditions. The addition of future research in parenting a child with disabilities is warranted as there are multiple gaps and limited research in specific areas. Overall, to become the expert, parents relinquished their own health to meet the ongoing needs and demands of their child with disabilities. Parents learn to advocate on their child’s behalf, and found that access to support and services, especially obtaining appropriate respite was an ongoing challenge. As well, fear of transition to adulthood was common in all literature exploring the experience of caregivers parenting a child with disabilities. Autism is a disability, and addressing these concerns is crucial to the well-being of parents parenting a child with autism.

#### *Disability and Living in a Rural Area*

According to Statistics Canada (2007) approximately 40% of the population of Manitoba lives outside of the metropolitan area of Winnipeg. A review of the literature on adults and children with disabilities revealed three common themes in the area of living in a rural area with disabilities. These themes include: (a) the difficulty families’ face in accessing services, (b) the increased financial burden, and (c) the diminished available support.

*Difficulty Accessing Services*

In an article published in 2007, Skinner and Slifkin utilized data from the National Survey of Children with Special Needs (NSCSN) designed by the National Centre for Health Statistics (NCHS). Through a large telephone survey, children with special needs were divided into rural and urban categories. In this study, rural residence was defined as those living outside of a metropolitan area. Overall, the authors highlighted many differences between rural and urban participants. Rural children with special health care needs tended to be seen at a clinic or health centre as opposed to a private doctor's office where their urban counterparts usually received their care. Furthermore, rural children were less likely to be treated by a paediatrician. A significant amount of rural parents reported a delay in seeking appropriate health care which is similar to Mayer, Slifkin, and Skinner (2005), who reported that not only were there transportation problems, financial barriers and care concerns for rural families, rural families also had a reduced perception of need for obtaining appropriate health care. Moreover, Skinner and Slifkin (2007) reported that a high number of rural parents believed that the type of care that was required was unavailable.

Buchanan, Stuijbergen, Chakravorty, Wang, Zhu, and Kim (2006) found similar results in their study on urban/rural differences in accessing health care for people with Multiple Sclerosis while O'Callaghan, McAllister, and Wilson (2005) found that 93% of the parents that participating in their study reported problems when trying to access speech pathology services. Furthermore, the further away the speech pathologist or health care provider was located, the less likely that it was accessed by individuals and families (Arcury, Gesler, Preisser, Sherman, Spencer & Perin, 2005; O'Callaghan et al.). Lack of



choice, lack of awareness and lack of public transportation were all described as barriers to accessing care (Buchanan et al.). In O'Callaghan et al.'s study, participating parents suggested increasing incentives to attract speech pathologists to rural areas, increasing funding to provide more services, providing travel bursaries to help subsidize the cost of travel, and increasing the awareness of the available speech services as proposed solutions to access barriers. In another study, Skinner, Slifkin and Mayer (2006) researched over 37,000 children and looked at the effect rural residence had on unmet dental needs for children with special health care needs. It was found that based on the professional recommendation of annual dental care for all children over the age of one, rural residents were significantly more likely to have unmet dental needs than their rural counterparts.

Due to accessing barriers to health care services in rural areas, Marcin, Ellis, Mawis, Nagrampa, Nesbitt and Dimand (2004) undertook a study looking at the use of telemedicine to provide paediatric care to rural areas. Telemedicine is becoming increasingly more popular due to physician shortages and geographical barriers that face so many rural families. Many specialty areas such as cardiology, dermatology and psychiatry have been able to take advantage of telemedicine in both the adult and paediatric age groups (Marcin et al.). Caregivers of 42 children with special health care needs were asked to participate in a telephone survey. The authors found that telemedicine had the ability to promote coordination between primary care physicians and subspecialists, reduced provider isolation, decreased travel time and cost, allowed patients to remain in care of their primary physician, and potentially decreased medical errors caused by delay or lack of communication.

With a specific focus on rural families with a child with cancer, Scott-Findlay and Chalmers (2001) conducted an exploratory, descriptive qualitative study with ten families who had a child diagnosed with cancer. At the diagnosis stage, many rural families dealt with long waiting periods for their primary care physician to transfer care to a tertiary care centre. Much frustration and stress were seen as there was a lapse in time from when their child was sick to the time of actual diagnosis. Furthermore, many parents were concerned with the ability to provide the best care for their child at home. Participants believed that the home care nurses and rural physicians were unqualified to perform the needed medical tasks such as caring for a central line and administering chemotherapy which left the parents to do the tasks on their own. In addition, a child with cancer had to stay longer away from home as their rural residence was too far away to get the appropriate help and support that was required. The authors concluded that “rural families that have a child with cancer face extreme challenges and adversities because of the lack of proximal resources” (Scott-Findlay & Chalmers, p. 214). Overall, parents advocate for their child and become experts in their child’s care and condition to provide the best possible life for their child. Living in a rural area is very unique and imposes its own challenges on top of the challenges already facing many families parenting a child with disabilities.

### *Financial Burdens*

Buchanan et al. (2006) completed a study on the urban and rural differences in access barriers to health care for people with multiple sclerosis. Recruiting over 1,500 participants, the authors found that rural residents reported a lack of money as a more significant barrier to them than to their urban counterparts. Overall, the authors concluded

that people living with multiple sclerosis in a rural area were much more likely to have barriers to accessing health care services than those participants who live in urban areas. Furthermore, Skinner and Slifkin (2007) reported that many rural parents did not have enough money to pay for services to access the health care needs for their child with special health care needs. Scott-Findlay and Chalmers (2001) also reported that as rural parents were more involved in the medical aspects of their child's care and experienced much more financial difficulty throughout the trajectory of their child's illness. Increased driving meant more money needed for gas and for living in a new city while the child underwent treatment or appointments. As well, parents had to quit their job or needed increased caregiver expenses to take care of siblings while the child was away from home. Increasing the available financial resources, coordinating appointments so there was less travel time, and increasing the awareness of health care professionals about the appropriate level of expertise that was found in rural settings were some of the identified needs voiced by parents. Overall, Skinner and Slifkin concluded that "rural families experience more system-level problems in accessing care, struggle more due to lower incomes, and spend more time obtaining and providing care for their children" (Skinner & Slifkin, p. 155).

#### *Decreased Support*

Several studies in the literature report a decrease in support found by parents parenting a child with disabilities and health care needs (Murphy et al., 2006; Scott-Findlay & Chalmers, 2001). Scott-Findlay and Chalmers found that rural families faced challenges of being away from home during the course of their child's cancer treatment. Families were forced to be alone and become familiar with a new city. Treatment kept the

child away from their rural home and all of their family support for days, weeks or even months at a time. Family members had to make work arrangements and other preparations for the care of siblings and pets. Significant planning was involved every step of the way, and even the simplest task of taking a child who lived in a rural area to an appointment required great preparation. Siblings were left at home and distant from their brother or sister and therefore, were not able to see them for long periods of time. Marital relationships were affected due to the strain of one parent being away with the child and the other parent who was left home to cope with the needs of the rest of the family and occupation. These results were similar to Murphy et al. who used purposive sampling to recruit 40 caregivers of children with developmental disabilities. The authors found that parents from rural areas illustrated less peer support than those caregivers from urban and suburban areas. Furthermore, Skinner and Slifkin (2007) concluded that transportation problems and lack of available child care were reported as unmet health care needs more frequently by rural parents than families living in urban areas. Moreover, children living in a rural setting were more likely to be cared for at home as opposed to those children with special needs living in metropolitan areas (Skinner & Slifkin).

Overall, rural families parenting a child with disabilities experience increased emotional strain, additional financial burdens, and take on the added responsibilities in the medical aspects of their child's care. Restricted access to services, coupled with the social isolation and lack of available funds make living in a rural area a risk for families caring for a child with disabilities. Lacking in this research is the experience of families with a child with autism and the effects of living rurally on family quality of life.

*Parenting a Child with Autism*

The final section of this literature review explores the complexities of parenting a child with autism and the unique challenges that face these families. The main areas of focus are: (a) the challenges, (b) the coping strategies, and (c) the lived experience of parenting a child with autism.

*The Challenges*

Multiple identified challenges to parenting a child with autism are shown throughout the literature (Davis & Carter, 2008; Durate et al., 2005; Gray, 1994; Montes & Holterman, 2007; Schieve et al., 2007). In 1994, Gray undertook an Australian study to identify the challenges faced by parents of children with autism. In this study the absence of language and the inability to communicate were symptoms that had the most impact on families. Although families managed, there were multiple times in which a parent could not understand their child's needs and parents were left frustrated. A further challenge identified by parents was the unpredictability of the child's behaviour within a public setting. Random tantrums, destruction, and making a mess were not uncommon for children diagnosed with autism. Not only did this behaviour take place in public settings, homes were often destroyed by children which made it very difficult for parents to keep a neat and tidy home. Increasing violence and inappropriate sexual behaviour were also identified as a source of stress for families (Gray). Majority of the children in the study by Gray developed obsessive traits in regards to food and toileting; these characteristics became a significant challenge for families, especially in a time of change or transition. Over ten years later, Davis and Carter (2008) investigated the unique child characteristics of children with autism and their association with parenting stress. For this study,

participants (including mothers and fathers) completed a questionnaire, were involved in an interview, and each child in the study was videotaped in an observational session. Overall, the authors were able to link high levels of stress and depressive symptoms in both mothers and fathers of children with autism. Deficits in social skills by a child with autism were found to have a direct link to both mothers' and fathers' stress. Although verbal functioning has been associated with paternal stress (Gray), Davis and Carter found that there was no association between cognitive and verbal functioning and stress in mothers or fathers of children with autism. The ability to generalize the findings of the study by Davis and Carter was limited to the lack cultural diversity and socioeconomic levels, and the small sample size.

Schieve et al. (2007) surveyed primary caregivers of over 78,000 children with autism and looked at the relationship between autism and parenting stress. Similar to Durate et al. (2005), Schieve et al. found a direct link between stress and parenting a child with autism. Parents who had a child with autism scored much higher levels of stress and aggravation than those parents parenting a child without special needs, and even those parenting a child with special needs without developmental problems. In another study, Lee, Harrington, Louie and Newschaffer (2008) looked at the quality of life in families parenting a child with autism. The authors determined that caregiver burden was significantly higher in the autism group and children with autism were more likely to miss school and less likely to participate in organized activity. In a 2007 study by Montes and Holterman, the authors sampled over 61,000 school-aged children. Although mothers of children with autism and mothers without a child with autism reported similar relationships with their child, mothers of children with autism were

found to have a child that was much harder to care for, was unable to have a relationship in which they were able to talk about things of value, and that the child “bothered them a lot more” than was reported of mothers without a child with autism.

Another parental challenge that was explored regarding parenting a child with autism was the ability for mothers to be able to get out of the house and have some time to their self. Published in 2006, Yantzi, Rosenberg and Mckeever conducted a study on the challenges that mothers faced while parenting a child requiring long term health care needs. The participants described multiple physical, social, and service challenges. Parents described a lack of spontaneity as children with special needs required a lot of planning to undertake any adventure. Lack of respite care, lack of family support, lack of knowledge and skilled caregivers, and lack of time away were social barriers of which parents in Yantzi et al.’s study were confronted. Working was a specific social challenge that the mothers in this study addressed separately. Some mothers chose to work full time, others part time, and some decided not to work. Some mothers reported work as respite and a break from living with a child with long term health care needs, while others felt that they should not work, rather care for their child at home. Service challenges identified by mothers revolved around respite care and the amount of money available to the mothers and their child. Limitations to this study included the lack of geographical differences between participants and the lack of ethnic diversity.

Taking a different angle of challenges that faced parents of children with autism, Montes and Halterman (2008) completed a study looking at the association of having a child with autism and loss of family income. This study used data collected from The National Household Education Survey – After School Programs and Activities Survey.

The authors found that the estimated annual income loss to be 14% or 6,200 dollars a year. This was a substantial loss for families especially since families that were parenting a child with autism often incurred significant added health care, educational, and behavioural expenses.

Overall, the literature identifies many challenges that families parenting a child with autism face and are forced to overcome. These challenges occur daily and lead to increased stress within the family. Addressing these challenges and focusing on coping strategies will ultimately lead to a better quality of life for both the child with autism and the family.

#### *Coping with a Child with Autism*

Published in 2007, Twoy, Connolly, and Novak looked into parenting, coping, and children with autism, with a focus on identifying the coping strategies used by these families. Through a descriptive quantitative study, 55 participants completed a questionnaire. The authors found that families routinely acquired and relied on the use of extended family members and close friends for support and as a method of coping. The majority (91%) of the respondents reported that they often sought out help and advice from other families in similar situations as an additional coping strategy in parenting a child with autism. Overall, similar to Montes and Holterman (2007), Twoy et al. found that “parents of children with autism spectrum disorder are resilient in adapting to the challenges of caring and raising their child with autism” (p. 257). Using extended family members, maintaining a positive outlook, reframing, seeking advice from families in similar situations, and inquiring information from family doctors were all identified and



used as active coping strategies by participation families. In addition, passive coping strategies such as watching television were identified approaches from the participants.

Prior to the above mentioned studies, Hastings, Kovshoff, Brown, Ward, Espinosa and Remington (2005) also explored the coping strategies in parents of preschool and school-aged children with autism and investigated as to whether there were any links between coping strategies and parental stress and health. Through the use of the COPE inventory and the Hospital Anxiety and Depression Scale, 74 mothers and 61 fathers participated in the research. In this study, four types of coping strategies were identified by the participants. Active avoidance coping which included substance abuse, avoidance, and blaming, were found to be used more by mothers and was associated with increased levels of stress, anxiety and depression. Positive coping methods that included humour and positive reframing showed to be the most beneficial strategy and found to have a negative association with mental health problems. Problem-focused and religious/denial coping strategies were also identified but found to have no association with parental mental health. Additionally, it was found that more mothers adapted the problem-focused strategy as compared to participating fathers. Moreover, the child's age or time in life did not have any relationship to the coping strategies used by the participants. In conclusion, the authors proposed that health care professionals should focus on "reducing parents' use of avoidant coping strategies and increasing their use of positive coping, perhaps by enhancing their positive perceptions of raising a child with autism" (Hastings et al., p. 388).

In 2006, Gray undertook a longitudinal study focusing on parental coping while parenting a child with autism. Through a qualitative ethnographic study, 26 families took

part in phase one of the study, with 20 families participating in the follow-up study conducted 8-10 years later. All data was collected through in-depth semi-structured interviews. Overall, the results show some significant changes over the 8-10 year period, which is in contrast to the findings of Hastings et al. (2005) which showed no coping style changes between different ages of children. In Gray's (2006) study, parents were found to use a lesser variety of coping strategies from initial interview to the second interview and the coping styles changed significantly from one interview to the next. Originally, the most used coping strategies were the use of treatment services and support from family. This was similar to a previous study by Gray (1994) in which family support and the use of treatment centres were the most utilized coping strategies by families parenting a child with autism. Special schools and treatment centres allowed families to obtain respite breaks, enabled children with autism to be taught skills to enhance home life and moreover, these centres became a significant source of reassurance and guidance for parents who were going through a stressful time. In Gray's (2006) longitudinal study, it was found that the strategies of treatment centres and special schools decreased for participating families over the period of 8-10 years. Similar to Hastings et al., Gray (1994) also found that although religion was identified as a specific coping strategy it was relatively uncommon in parents who were parenting a child with autism. Gray (1994) concluded that no one specific strategy was identified as working better than another. Every child with autism was unique as was the way that parents cope when parenting a child with autism. Just as Gray (2006) found, coping strategies were shown to change over time and change from family to family.

Overall, the use of multiple coping strategies is often seen within families and not related to any one particular outcome. Due to increased stress and the impact on quality of life, incorporating a variety of coping strategies is crucial to the well-being of families. Overall, as seen in the literature, the majority of the families feel that they are successful in coping, and parents show incredible strengths and adaptation when living with a child diagnosed with autism.

### *The Lived Experience*

Fortunately, parenting a child with autism is not always full of challenges and burdens; many families experience joy and satisfaction when parenting their child. Bayat (2007) found that families parenting a child with autism were involved in a variety of resilient processes such as mobilizing resources, becoming united as a family, and gaining a better appreciation of life. Several other authors have looked at the lived experience of parenting a child with autism. Authors including Gray (1994), Cashin (2004), and Woodgate, Ateah, and Secco (2008) have taken the phenomenological approach to studying autism and the family. Gray undertook a study to describe the experience of Australian parents coping with a child with autism. This study included the nature of the stresses, the coping strategies used by parents, and coping strategies that were most effective in helping families manage successfully. Overall, it was found that parents managed the best that they could and that there was not one single strategy that was more influential than another. Parents felt that they were successful in coping and that their lives were rewarding and valuable with whatever strategies they incorporated. In another Australian study, Cashin embarked on a hermeneutic phenomenological study to explore the lived experience of parenting a child with autism. Here the authors

discovered that having a child with autism would overtake the parents' lives and change their way of being in the world. Parents found that they experienced less of everything and that they were sucked into a "vortex of autism." Parents voiced concerns about having less spontaneity, less social contacts, less time to themselves, and less material possessions. In 2004, DeGrace conducted a qualitative study to understand families' experience of parenting a child with autism. The author found that these families lived their lives around the needs and desires of the child with autism. They lived moment to moment and relied on routines around the child to meet the demands of daily life.

Three years later, Woodgate and colleagues (2008) undertook a hermeneutic phenomenological study to explore the lived experience of Canadian parents who had a child with autism. Through the interviews from 16 families and similar to the findings of Cashin (2004), the major essence of parenting a child with autism was the theme of living in a "world of our own". Just like children with autism were encased in a world of their own, parents in Woodgate et al.'s study experienced similar feelings of being alone and isolated. However, what was unique to Woodgate et al.'s study was that from the perspectives of the parents, their sense of isolation was not self-imposed, but mainly the result of external sources. Parents described the importance of developing intense parenting skills in order to help facilitate their children's development. Parents became "super" parents and immersed themselves into helping their child develop their full potential. Parents' perspectives on "normal" development milestones were also described and celebrating these milestones was a sense of accomplishment and a way of coping for participating families. Overall, the literature on the lived experience of parenting a child with autism is quite limited and without focus on families that live in a rural area. It is

essential that professionals caring for a child with autism become aware of the concerns and meanings caregivers have regarding parenting a child with autism in order to provide families with the appropriate direction and enable success in their child.

### Chapter Summary

Overall, families parenting a child with autism are resilient and make the best of the meaning of autism; they experience daily joys and struggles along this lifelong journey. Unfortunately, there are no studies with a focus on living in a rural area and parenting a child with autism. Due to the limited qualitative research done on the lived experience of parenting a child with autism, future studies are recommended to understand the entire essence of parenting a child with autism. This literature review provided the support for an exploration of the lived experience of families parenting a child with autism while living in a rural area. This study is best suited for in-depth interviews guided by the ideology of phenomenology. The next chapter explores the conceptual framework that guided this phenomenological inquiry.

## Chapter III: Conceptual Framework

### Introduction

Chapter three outlines the conceptual framework of the Life Needs Model created by King, Tucker, Baldwin, Lowery, LaPorta and Martens (2002). In hermeneutic phenomenology, a conceptual framework is not used to orientate the study or create the research questions, rather the framework is used to focus the inquiry and guide the direction of determining the sample, subjects, and research questions (Lopez & Willis, 2004). The participants were not biased by the conceptual framework; however, the framework was used to interpret the research findings (Lopez & Willis, 2004). This section provides a brief overview of the Life Needs Model.

#### *The Life Needs Model*

Participation is essential to children's development. Through participation children "acquire skills and competencies, connect with others and communities, and find purpose and meaning in life" (Law, 2002, p. 640). Disability has significant impact on children's participation. Children with disabilities are at an increased risk for restricted participation (Brown & Gordon, 1987). Children with disabilities spend more time in informal activities such as reading and quiet recreation and less time in formal activities and active recreation (Brown & Gordon, 1987; Imms, Reilly, Carlin, & Dodd, 2008). In 2002, King et al. formulated the Life Needs Model of paediatric service delivery in hopes to distinguish the services needed to support community participation and quality of life for children with disabilities.

With an initial aim of restructuring and extending the organizational vision of Thames Valley Children's Centre, a regional children's rehabilitation centre, the authors

developed a model highlighting the importance of needs, participation, and quality of life for children with disabilities. With a developmental, socio-ecological background, this model delves into a holistic service delivery framework that incorporates the needs of children and youth, their families, and their communities integrating the personal, interpersonal and external spheres of life

To be able to develop the appropriate services for rural families of children with autism, it is vital for researchers to return to the parents themselves to explore their unique situations to determine the ideal services within the parents' context. In particular, because research in rural areas is limited, it was crucial to specifically look at the experience of rural parents of children with autism. The hope was to uncover their day to day routines, parenting styles, and specific needs. By exploring the lived experience, researchers are able to enable parents to advocate for appropriate services to increase quality of life for their child and family.

The Life Needs Model is a holistic needs based framework that describes the major types of service delivery needs of children and youth with disabilities, their families, and their communities to meet the long term goals of community participation and quality of life. The Life Needs Model focuses on the strengths of children and families, the idea of real-world function, and participation through specific transition points, with the proposal of creating nurturing environments to maximize community participation. Services are provided by multiple systems which makes the model transdisciplinary. The five service groups identified by the authors are: (a) those addressing communities' needs for information and education, (b) those addressing parents' and family members' needs for support, information, and skill development, (c)

those addressing the clients' needs, (d) those that focus on the clients' applied skill set, and (e) those focusing on clients' foundational skills. Service groups encompass the external, interpersonal and personal spheres of life. These service groups serve as a guide for addressing the needs of families parenting a child with autism in a rural setting. Event life transitions, where client and family needs typically change, and age-specific services needs are highlighted throughout the model. As well, the model provides a list of short-term goals and King et al. clearly identified the ultimate long term goals as community participation and increased quality of life. While exploring the lived experience of parents parenting a child with autism, the main objective was to understand how daily life was characterized by parents. Included within day-to-day life were the child's needs, the family's needs, the ability to participate, and the overall quality of life for the child diagnosed with autism.

Although King et al. (2002) do not specifically identify the nursing education required; they do delve into the education of multiple providers. The authors believe that "service providers must have the skills and knowledge to provide family-centered care" (King et al., p. 71) and that providers must be both specialists and generalists. Service providers are seen as "agents of change...who teach foundational skills, modify environmental constraints, and encourage the use of applied skill sets within appropriate school, home, and community contexts" (King et al., p. 71). The services that are to be provided must be comprehensive and in a continuous fashion, that incorporates a variety of community agencies. As well, ongoing community education is required so that community members are well educated in knowing how to eliminate the barriers to participation.



The Life Needs Model is easy to follow and feasible to implement into practice. The authors outline each area of the model and clearly show how to incorporate it into the clinical setting. Each role of the service providers are identified and the model is suitable for children of all ages and of all disabilities. They provide the reader with potential uses and offer a concrete example of the model's use. King et al. (2002) believe that "the model has the potential to be of great benefit to health planners, managers, service providers and recipients, researchers, and educators in the field of childhood disability" (p. 69). Health care professionals may use this model to educate students about the needs of children with disabilities and service organizations may use the model to evaluate, improve, and expand services to increase community participation and quality of life for children and youth with disabilities. This model also provides an ideal vision for communities. As outlined by the authors, a downside to the model is the potential high costs to fully integrate the model within a community. The authors justify this drawback by stating that "a vision of ideal services is necessary" (King et al., p. 73). The authors further clarify that a community should see the whole picture in order to provide an overall spectrum of services. Health system planners and decision makers need to examine the existing services to determine the gaps in service, in hopes of facilitating new services to fill in the missing pieces.

By implementing the Life Needs Model, service providers should see a clear increase in community participation and quality of life in children with disabilities. Batorowicz, McDougall, and Shepherd (2006) found that through the implementation of the Life Needs Model in two community partnership programs, children with disabilities, their families, and communities reported a multitude of benefits that overall increased

children's participation and enhanced the child's quality of life. The Life Needs Model is also used by the Thames Valley Children's Centre and King, Tucker, Baldwin, and LaPorta (2006) found that the theory aided in the refinement of existing clinical programs and services. Furthermore, the model was used to develop new clinical programs and services such as Kids on Track and Youth En Route. Moreover, the model has provided a framework for the role of the therapist, often changing the therapists way of thinking, assisting the therapist with client goal setting, informing parents about upcoming transitions points, and informing parents about broader support that may be available. Furthermore, the Life Needs Model is used in developing community awareness and service delivery partnerships. Overall, the Life Needs Model provided an appropriate framework in which to guide this study.

#### Chapter Summary

The Life Needs Model provides a detailed service map of the needs of paediatric rehabilitation services. King et al. (2002) have tried to fill an existing literature gap by providing this paediatric service delivery model for children with disabilities, their families, and their communities. The Life Needs Model provided a framework for this study, and this model served as a guide for interview direction. It is crucial to recognize the services needed for the population of children with disabilities and ensure that these needs are met within the rural setting. Through this study, the needs that rural families face in parenting a child with autism were determined. As needs are identified, services can be put in place to enable children to gain an increase in participation and therefore, enhance their quality of life. The following chapter describes the methodology of this research study which includes the philosophical framework of van Manen (1990).

## Chapter IV: Methodology

### Introduction

This chapter provides insight into the research methodology that was used to guide this qualitative study. The philosophical framework of van Manen (1990) is explained and refers to the methodology, while the process for carrying out the research is the method. Included within the method description is the research design, sample criteria, recruitment of participants, research setting, data collection methods, approach to data analysis, strategies to achieve trustworthiness, and ethical considerations.

### *Philosophical Framework*

Not only is phenomenology a research method, it is also a philosophy (Dowling, 2007). The philosophy of hermeneutic phenomenology as discussed by van Manen (1990) was used to guide this phenomenological inquiry. Hermeneutic phenomenology is “essentially a philosophy of the nature of understanding a particular phenomenon and the scientific interpretation of phenomena appearing in text or written word” (Speziale & Carpenter, 2007, p. 88); phenomenology being the lived experience and hermeneutics being the interpretation of the essence of life (van Manen).

Combining both the descriptive phenomenology of Husserl and the interpretive phenomenological philosophy involving the deep understanding through language and meaning, the aim of hermeneutic phenomenology is to explore human phenomena in order to understand the structure or essence of the lived experience (Dowling, 2007; Ray, 1994; Speziale & Carpenter, 2007). Hermeneutic phenomenology is a human science that explores being in and on this world by creating meanings of the expressions of how humans exist in the world (van Manen, 1990).

Hermeneutic phenomenology as described by van Manen is a newer philosophy combining the works of Husserl and Heidegger grounded in German and Dutch philosophical traditions (Ray, 1994). To develop a true understanding of the work of van Manen, the works of the founding authors will be discussed.

### *Husserl's Transcendental Phenomenology*

As an alternative to the empirically based scientist quantitative paradigm, a mathematician named Edmund Husserl (1859-1938) is attributed to the development of transcendental phenomenology (McConnell-Henry, Chapman, & Francis, 2009). Husserl is credited with introducing the “lived experience” or experience in the “life-world” (McConnell-Henry et al.). According to Husserl, the goal of phenomenology is “the rigorous and unbiased study of things as they appear in order to arrive at an essential understanding of human consciousness and experience” (Dowling, 2007, p. 132). In transcendental phenomenology the aim of the researcher is to achieve the Husserlian concept of transcendental subjectivity. To achieve transcendental subjectivity, the “impact of the researcher on the inquiry is constantly assessed and biases and preconceptions neutralized, so that they do not influence the object of the study” (Lopez & Willis, 2004, p. 728).

Transcendental phenomenology is descriptive in nature and to find the true essence of the “lived experience” it is necessary for one to adopt the concept of bracketing. Bracketing requires the researcher to suspend all beliefs of the outer world and all past knowledge of the phenomenon of study leaving it neither confirmed nor denied. Putting aside one’s beliefs is an attempt to leave only the consciousness in an effort to study things as they appear pre-reflective and free from all cultural contexts

(Dowling, 2007). Bracketing is Husserl's effort to objectify research findings in order to achieve scientific rigor, essential to the positive paradigm (McConnell-Henry et al., 2009). Descriptive phenomenology involves a search for the essence using free imaginative variation, being in a state where the phenomenon can be described without construction, interpretation or explanation (Maggs-Rapport, 2001). Due to the Cartesian concept of duality, Husserl supports the idea that the mind and body are mutually exclusive.

### *Heidegger's Hermeneutic Phenomenology*

Several years after the development of Husserl's transcendental phenomenology, Martin Heidegger (1889-1976), a student of Edmund Husserl, developed his own approach defined as hermeneutic phenomenology (Maggs-Rapport, 2001; McConnell-Henry et al., 2009). Heidegger focused on understanding and interpreting phenomenon rather than describing it. The focus of his work shifts to the meanings of human experience rather than a description of core concepts (Lopez & Willis, 2004). Heidegger rejected bracketing; instead claiming that one is inseparable from the world of being, and that it is impossible to have interpretive research free from the influence of the researcher (McConnell-Henry et al.). In hermeneutic phenomenology, time and context shape one's understanding of the phenomenon (McConnell-Henry et al.). Instead of believing in the mind-body duality, Heidegger advocated for Dasein, a concept translated as "being-there" (Maggs-Rapport) and can refer to a single person or a general way of being (Annells, 1996). He also supported the hermeneutic circle which "relies on the circular movement from the whole to the parts, incorporating the contributions of all deconstructing and then reconstructing, resulting in a shared understanding" (McConnell-

Henry et al., p.11). In Heidegger's hermeneutic phenomenology, the researcher aims to gain an ontological perspective of the experience of the participants.

#### *Limitations of van Manen's Methods*

In all research methodologies there are limitations and it is vital for the researcher to acknowledge these specifically to the methodology of choice. In general, phenomenology does not attempt to predict, generalize or generate theories (Speziale & Carpenter, 2007); instead it aims to create a deeper understanding of the nature or meaning of everyday experience (van Manen, 1990). This is important as nurses are concerned with determining human experience and gaining a greater understanding of families' perspectives in order to increase their quality of life.

#### *Appropriateness of van Manen's Method for this Study*

van Manen's (1990) phenomenology was an appropriate approach for this study as the researcher had prior experience with and knowledge of the phenomenon. Unfortunately, this knowledge was limited in scope and further understanding was warranted. van Manen's method has been widely adopted by a variety of health care professionals, sociologists and social scientists, including nurses. His method is flexible and versatile as seen by its use in a range of research scenarios including that of exploring midwives' ways of knowing during childbirth (Hunter, 2008), the lived experience of critically ill patients' family members (Wagner, 2004), the lived experience of adolescents with depression (Woodgate, 2006), the lived experience of parents who have a child with autism (Woodgate et al., 2008), and the value of parenting (van Manen, 1990). van Manen's method permits for an immediate exploration of the phenomenon and allows for even the most comprehensive issues to be explored with a detailed

technique. According to van Manen, interviews serve a dual process by being able to develop relationships about the meaning of an experience and the ability to gather narrative data that will enhance the understanding of the phenomenon of study (van Manen). The intent of this study was to gain a deeper understanding of the meaning of the experience of parents parenting a child with autism in a rural area.

### Research Design

Building on the work of Woodgate et al. (2008), a qualitative phenomenological study that sought to explore the lived experience of rural parents of children with autism was conducted. Depth and detail are crucial to qualitative research and “emerge through direct quotation and careful description” (Patton, 1980, p. 22). Qualitative measurement seeks to portray what people have to say in their own words to “find out what people’s lives, experiences, and interactions mean to them in their own terms and in their natural settings” (Patton, p. 22).

The aim of phenomenological research as described by van Manen (1990) is to translate the lived experience into words and meanings to achieve true meaning of the experience. Phenomenology was the chosen methodology as the personal voice and experience of these families provided rich, descriptive data. It was through parents’ thoughts, feelings, experiences, and meanings that provide the greatest insight into the chosen phenomena. The methodology as described by van Manen was used to address the purpose of this study and guide the data collection, analysis, and interpretation. van Manen describes six research activities that directed each step of this study (see Table 1).

Table 1. The Research Process

<b>van Manen’s (1990) Methodological Themes</b>	<b>Research Activities for this Study</b>
1. Turning to a phenomenon which seriously interests us and commits us to the world.	<ul style="list-style-type: none"> <li>- Orientation to the phenomenon through the conduction of a literature review, formulation of the research questions, and determination and description of the assumptions.</li> <li>- Creation of the proposal and recruitment of participants.</li> </ul>
2. Investigating experiences as we live it rather than as we conceptualize it.	<ul style="list-style-type: none"> <li>- Exploration of the phenomenon.</li> <li>- Generation of data first by determining personal experience, and then through the interviews of parents that experience the lived knowledge.</li> <li>- Consultation of phenomenological literature and research done on the chosen phenomenon.</li> </ul>
3. Reflecting on the essential themes which characterize the phenomenon.	<ul style="list-style-type: none"> <li>- Engagement in phenomenon reflection through the conduction of a thematic analysis of the lived descriptions.</li> <li>- Determination of thematic statements that portray the phenomenon.</li> </ul>
4. Describing the phenomenon through the art of writing and rewriting.	<ul style="list-style-type: none"> <li>- The act of phenomenological writing and rewriting.</li> <li>- Creation of thick descriptions and interpretations of the lived experience.</li> </ul>
5. Maintaining a strong and orientated pedagogical relation to the phenomenon.	<ul style="list-style-type: none"> <li>- Maintaining the research questions and purpose of the study and its relation to nursing.</li> </ul>
6. Balancing the research context by considering parts and whole.	<ul style="list-style-type: none"> <li>- Movement from themes to the entire transcript of individual interviews</li> </ul>

### Sampling and Recruitment

This study took place in rural Manitoba and incorporated purposive sampling to seek out parents from 26 families parenting a child with autism in rural Manitoba. The



strength of purposive sampling was in selecting information-rich cases that were immersed in the chosen phenomenon. The intent of such technique was not to generalize, but to arrive at an in-depth understanding of the phenomenon, and hence the reason for a smaller sample (Patton, 1990; Sandelowski, 1995). Although a sample of parents from 10 to 12 participants was proposed, the final sample size of 26 families was determined by the completeness of the data and the achievement of theoretical saturation. Inclusion criteria included parents who: (1) were able to speak, read and write English, (2) had a child who was under the age of 18 and had been diagnosed with autism, and (3) who lived in a rural setting which included all communities outside the Perimeter of Winnipeg, Manitoba.

An intermediary at both St. Amant and Children's Special Services (CSS) was asked to assist with the recruitment of participants. This person was responsible for the initial contact of all eligible participants by sending out a letter of invitation (see Appendix A). If parents were interested in participating, the participants initiated contact with the researcher through phone, email or returned mail. The researcher then followed through with a phone call (see Appendix B). The intention of this phone call was to explain the purpose of the study and to explore the parent's willingness to participate. Potential participants then agreed or declined participation. All potential participants agreed to participate. When a parent was willing to take part in the study, a convenient interview time and location was established. All participating parents were asked to take part in two semi-structured, open-ended interviews. Study information and consent forms were distributed prior to the commencement of the first interview. The researcher conducted all interviews and with permission, all interviews were tape recorded as

quotations were the primary source of data in qualitative research. Interviews and field notes were transcribed and data analysis occurred concurrently with data collection.

### Research Setting

Interviews were conducted where the families desired so that they would be comfortable throughout the interview process. During the interview it was important to create an environment free from distractions and with minimal interruptions. All interviews except for two were conducted at the homes of the participants. For those other two interviews, one took place at a restaurant on the participant's lunch break and another took place at the participant's home. Being able to visit the participants' homes and see where they lived in terms of community, set an excellent context in which to conduct this study. To see where these families lived, to meet siblings, pets and the child with autism added to the understanding of the lived experience and to truly gain an appreciation of living in a rural area and what that meant to participating families. Being able to meet with participants in their homes allowed for a deeper understanding of the meanings parents ascribe to parenting a child with autism.

### Data Collection Methods

Three primary sources of data collection were utilized within this study. These included open-ended interviews, a demographic form and the researcher's personal field notes.

#### *In-depth Individual Interviews*

To understand the lived experience through phenomenology, parents of children with autism took part in audio-taped, in-depth, face to face individual interviews conducted by the researcher. The interviews were semi-structured, open-ended to allow

for the greatest detail and the opportunity for parents to speak in their own words rather than that of the researcher. Gaining respect and mutual trust between the researcher and participant allowed for a successful interview and the ability to access closely held information (Speziale & Carpenter, 2007). In order to facilitate respect and trust, taking the time to build a relationship and rapport with parents became a crucial step of the research process. Additionally, reflexivity through the use of a researcher's journal was employed throughout the interview process. Reflexivity, also known as self-reflection, is the ability of the researcher to be reflective on one's influence by analyzing it to enhance the data collection. Overall, the general outcome of an interview is to understand the meaning of the experience for those who are a part of it and not to understand 'just the facts' (Speziale & Carpenter). During the interviews, parents were asked to describe what life was like for them while parenting a child with autism. They were also asked to describe how living in a rural area affected life with a child with autism. Open-ended probes were used to elicit detailed stories of the lived experience (see Appendix C). Patience and silence were exercised to promote recollections and allow the participants to proceed with a story or give any further thoughts on an issue.

The first interview sessions with parents took place over three and a half months and occurred between January and April 2010. These interviews facilitated the collection of the rich data exploring the essence of parenting a child with autism. The majority of the participants were female, married, and stayed at home with their child. Interviews ranged from 37 to 135 minutes with an average of 83 minutes. All care was given to minimize errors and reduce background noises and interruptions. Tape recording equipment was checked regularly and extra batteries were brought to each interview. A

second interview session gave participants the opportunity to further expand on any thoughts or ideas or to add anything that they felt vital to the true meaning of the study. In addition, it enabled the researcher the opportunity to clarify any previous information and to validate themes to allow for as much interpretive insight as possible (van Manen, 1990). The second interview sessions with participants occurred between June and July 2010. All but one family participated in the second interview. Follow-up interviews took place over the phone and took up to 50 minutes with an average of just over 15 minutes. All participants reported that the study results were clear and an accurate representation of their experience.

#### *Demographic Questionnaire*

The second source of data was taken from a demographic questionnaire developed particularly for this study (see Appendix D). Parents were asked to fill out this questionnaire prior to being interviewed. Included in this form were questions on the participants' age, marital status, ethnicity, number of children in the household and their ages, age of the child diagnosed with autism and the age of diagnosis, and distance away from the urban city of Winnipeg, Manitoba. The form took five to ten minutes to complete and any questions asked by participants were answered while the form was filled out. All participants filled out the demographic form.

#### *Researcher's Journal*

The final source of data collection was from a journal kept by the researcher. This journal included all field notes and thoughts and feelings before and after each interview. The journal was also used to facilitate rapport with the participants by reflecting on cultural differences, attitudes, feelings and values by the researcher. Observations were

recorded; reflections and potential arising themes from the work in progress were also included. Furthermore, the researcher included personal assumptions regarding autism and living in a rural setting. This cognitive process of putting down one's own beliefs to prevent judgements on what one has observed and heard is called bracketing (Speziale & Carpenter, 2007) and is vital in the phenomenology method. It is essential for the researcher to remain cognizant while collecting and analyzing data so that the interpretation remains a reflection of the participant rather than of the researcher's personal beliefs. Although the researcher's journal was a self-reflective process, the journal was shared with the researcher's advisor to assist in data analysis and interpretation.

#### Data Analysis

All interviews and field notes were transcribed verbatim and analyzed. Over 2000 pages of transcribed data emerged from the primary interviews. Data interpretation and analysis “involves making sense out of what people have said, looking for patterns, putting together what is said in one place with what is said in another place, and integrating what different people have said” (Patton, 1990, p. 246). According to van Manen (1990), theme analysis refers “to the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work (p. 78). Although themes occur frequently within a text, analysis is not simply a counting or coding of selected terms; instead it is a process of “insightful invention, discovery or disclosure – grasping and formulating a thematic understanding is not a rule-bound process but a free act of ‘seeing’ meaning” (van Manen, p. 79). Themes are understood as

the structures of experience, a form of capturing the phenomenon the researcher is attempting to understand (van Manen).

Thematic statements were isolated using van Manen's (1990) selective highlighting approach. In this approach the search for themes or structures of the experience involved selecting the highlighting sentences or sentence clusters that stand out as thematic of the experience. By lifting appropriate phrases and capturing specific statements, the meaning of the experience was captured. Once the themes have been identified, the researcher and the participant worked in collaboration in follow-up reflective conversation. The researcher and the participant "attempt to interpret the significance of the preliminary themes in the light of the original phenomenological question" (van Manen, p. 99). This interpretive conversation occurred during the second interviews with participants when the draft description of the phenomenological themes were utilized as a starting point for the further sharing of the lived experience. The end result was the development of a narrative description of the essence of the parents' experience. Data collected from the demographic form was summarized and described using descriptive methods.

As this study was part of a Master of Nursing thesis project, collaborative analysis between the researcher and advisor was ongoing through discussion about themes including clarification, examination, and re-interpretation (van Manen, 1990). Not only did this provide the student with the guidance and experience in thematic analysis, it was a method of ensuring that the interpretation of the material was an appropriate representation of what the participants shared. Only the student researcher and her

advisor read the interviews and had access to the data that was identifiable to each participant.

### Methodological Rigour

Rigour in qualitative studies is a critical component to the research process. Strategies for enhancing the integrity of the study occurred throughout the procedure. Due to the fundamental differences in philosophical underpinning and the goals of the two main paradigms, qualitative studies cannot use the same terms to evaluate reliability and validity as in the quantitative approach (Polit & Beck, 2008). However, the ability to demonstrate rigour in a research study is imperative to the creditability of that study. Several authors have adapted different means of measuring rigour and validity in the qualitative methodology (Maggs-Rapport, 2001; Meyrick, 2006; van Manen, 1990; Whittemore, Chase, & Mandle, 2001).

Parallel to reliability and validity in quantitative research, standards for the trustworthiness is a unique approach adapted to qualitative research (Lincoln & Guba, 1985). The criteria developed by Lincoln and Guba were used to determine the trustworthiness of this study. The criteria addressed in this research study were credibility, dependability, confirmability, transferability, and authenticity.

### *Credibility*

To preserve the credibility of a study, the researcher strives to instil confidence in the truth of the data and the interpretations produced (Polit & Beck, 2008). In this study, prolonged engagement with the participants and the data was the method of establishing credibility. Interviews occurred on two separate occasions, with the first interview occurring over 37 to 135 minutes. Interviews continued until data saturation was

achieved. Data saturation occurred when there was repeated replication of information and no further themes or essences emerged from the participants (Speziale & Carpenter, 2007). Although saturation was obtained prior to completion of the 26<sup>th</sup> interview, it was important to include all families that responded to the letter of invitation as to create greater diversity of the sample. As a researcher, taking the findings back to the participants not only validated the essence but determined the accuracy of the description and thus, enhanced the believability of the findings and established credibility to external readers. Subsequent immersion with the data occurred over multiple months. Findings were studied, discussed and reviewed with the thesis advisor which furthermore, enhanced credibility.

#### *Dependability*

Dependability, similar to reliability, refers to the ability to replicate the findings over time and over conditions (Lincoln & Guba, 1985). Dependability is met once credibility of the findings is determined (Speziale & Carpenter, 2007). Continued discussion, revision, and regular communication with the thesis advisor contributed to achieving dependability within this study.

#### *Confirmability*

An audit trail is a qualitative researcher's way to document the process of confirmability of a study. Confirmability refers to objectivity and is concerned with reflecting the true findings of the participants without the biases, motives or perspectives of the researcher (Polit & Beck, 2008). For this study an audit trail was created through the audio-tape recordings of interviews, the transcript records, a written record of the data



analysis progression, the recording of field notes, and the journal of reflection and therefore, achieved confirmability.

#### *Transferability*

The fourth criterion is that of transferability or “fittingness” and is the ability of the findings to have meaning to others in similar settings (Speziale & Carpenter, 2007). Within this study, transferability was met by allowing the participants to understand the processes that occurred to determine how the interpretation of the data was achieved. In addition, comprehensive field notes were documented to provide ample descriptive data within the findings for others to evaluate the ability to find similar meanings in other contexts (Polit & Beck, 2008).

#### *Authenticity*

Authenticity is the final criterion in enhancing quality and integrity in qualitative research. Authenticity is the ability of the researcher to fairly and faithfully report the experiences of the participants as they are lived (Polit & Beck, 2008). Going back to the participants to validate the findings achieved authenticity in this study.

In conclusion, to establish trustworthiness the researcher must earn the trust of the readers. Integrity within research begins with the research questions and continues throughout the entire procedure. In this study, verification and discussion of findings was continuously communicated between the thesis advisor and the student researcher. Ongoing openness and flexibility throughout data collection and analysis were maintained with continued reflection to search for the true meaning of the essence. Regular communication with the thesis advisor provided verification and furthermore, enhanced trustworthiness.

### Ethical Considerations

Given the unpredictable nature of qualitative research, ethical dilemmas within issues surrounding informed consent, anonymity and confidentiality, data generation, publication, and researcher-participant relationships must be acknowledged and given special attention (Speziale & Carpenter, 2007). To remain ethically sound when working with human subjects, the ethical principles of autonomy, justice, non-maleficence, and beneficence were implemented. The following section details the ethical issues that were considered in this study.

### *Ethics Review*

The purpose of an ethics review is to ensure that the ethical principles of conducting a research study are fulfilled. The research proposal was reviewed by the ethics committee at the University of Manitoba to maintain protection of all participants. In addition to being the main researcher of this study, the researcher was a Registered Nurse required to abide by the Canadian Nurses Association Code of Ethics for Registered Nurses. As well, the researcher signed a Privacy Health Information Agreement (PHIA) with the Winnipeg Health Authority. Prior to conducting this study, approval was obtained from the thesis committee, The University of Manitoba Education/Nursing Research Ethics Committee, and the St. Amant Research Centre. As the researcher did not have access to the names of potential participants through the CSS, no further ethical consultation was required by CSS. The ethical principles of autonomy, non-maleficence, beneficence, and justice will now be discussed.

*Autonomy*

To maintain the principle of autonomy, it was crucial to recognize the right of participants to freely choose whether to commence and continue with participation in this study. Once participation began, it was crucial to ensure that participation remained voluntarily. Informed consent was obtained from all participants through the signing of a consent form (see Appendix E) and verbal consent was maintained throughout the interviews. Informed consent meant that the participants had been thoroughly informed about the research study, were capable of comprehending the information, and had the power to choose whether or not they wished to participate or decline participation (Speziale & Carpenter, 2007). Although participants signed a consent form, informed consent was an ongoing process occurring through each step. Furthermore, all participating parents were made aware that their participation was voluntary, that they would not be harmed, and that they may withdraw at any time without penalty. Participants were allowed to decline the second interview. All but one participant completed the second interview. Although multiple attempts were made to contact this parent, this participant was unavailable and therefore, did not complete the follow-up interview.

Further strategies were implemented to uphold the principle of autonomy. No dual relationships were present in the study; potential participants were initially notified of the study by letter from an organization that had no affiliation with the study. To prevent potential participants from feeling coerced into the study, the primary researcher did not have access to any names until participants contacted the researcher by email, telephone or returned mail. Participants were all over the age of 18 and voluntarily consented to be

interviewed. Interviews occurred at a time and location convenient to the participant and the approximate length of the interview was discussed prior to obtaining consent. Prior to obtaining consent, a description of the study purpose, methods of data collection and time commitments were discussed with the participant. The researcher's student status, thesis advisor's name, credentials, and university affiliation were also explained to the parents. Contact numbers for the researcher, advisor and the Human Ethics Secretariat were provided to each participant. As well, all information about the study was discussed verbally with ample time to answer any questions. Furthermore, risks and benefits to this study were discussed with the participants prior to attaining consent.

#### *Non-maleficence*

To maintain the principle of non-maleficence, the researcher must ensure that neither the researcher nor the research does any harm to the participant (Polit & Beck, 2008). Throughout this research project it was vital for the researcher to keep an ongoing awareness that the main purpose of the study might require that participants remember past and present experiences which had the potential to be difficult and evoke unpleasant feelings and memories. Due to the qualitative nature, "the psychological consequences of participating in a study are usually subtle and thus require close attention and sensitivity" (Polit & Beck, p. 170). Additionally, participants were vulnerable to losing personal and family privacy. The use of in-depth interviews presented both risks and benefits to the participants; therefore, participants were presented with a discussion regarding the nature of the interview and given plenty of opportunity for questions and further clarification. Furthermore, all participants were given the opportunity to withdraw at any point during this study.

When conducting qualitative interviews and eliciting past memories, the possibility of distress occurring is always a potential adverse reaction. Some parents may become more aware of their feelings and this may potentially cause stress and unwanted emotions. Care was taken to exercise sensitivity, and respect was honoured. Empathy and objectivity were also emitted by the researcher (Holloway & Wheeler, 1995). The researcher remained non-judgemental and eliminated any personal values or biases that could affect the research.

Due to the potential distress, a plan for intervention was required prior to any interviewing. In the event that there were some unpleasant feelings, upsetting memories or increased stress, the plan was to stop the tape recording, validate the participant's feelings, and provide time. If the participant was able to regroup and continue, the tape recording continued and the interview proceeded. However, in an event that the participant was unable to continue, the interview ended and was proposed for another date. Fortunately, all participants were able to complete the interviews, with occasional stops due to bathroom breaks, phone calls or parents needing to attend to their children.

### *Beneficence*

Doing good and preventing harm, also known as the ethical principle of beneficence, applies to providing confidentiality and anonymity to all research participants (Speziale & Carpenter, 2007). In research, beneficence is maintained by ensuring that the research is of maximum benefit to the participants while minimizing any potential harm (Polit & Beck, 2008). Participants were assured confidentiality and anonymity, and parents were always treated with respect and dignity. Every effort was made to ensure that potential participants had sufficient knowledge to make an informed,

autonomous choice. All participants were presented with both written and verbal information regarding this study, including a description of all potential risks and benefits. Additionally, participants were always encouraged to seek clarification and ask questions on an ongoing basis.

### *Justice*

The ethical principle of justice refers to the participants' right to fair treatment, the right to privacy, and the treatment of each person in accordance with what is morally right and proper (Polit & Beck, 2008). In regards to research involving humans, distributive justice requires that the researcher does not neglect or discriminate against individuals or groups who may benefit from advances in research (Polit & Beck). The voice of parents of children with autism from rural areas was lacking in the literature. For this study, it was hoped that all families who were parenting a child with autism while living in a rural area had the opportunity to participate. Due to the large geographical area and staff resources at CSS, some families did not become aware of this study. However, the goal of the researcher was to make every attempt to include all families that were willing to participate regardless of where they were located.

Moreover, according to the principle of justice, it was imperative of the researcher to treat people who declined from the study after agreeing to participate in a non-prejudicial manner and to honour all agreements made with participants including any honorariums or stipends. Except for the one parent that was unavailable for the second interview, no parents declined this study. Although this participant did not complete the second interview, the honorarium was still sent out to this mother. In addition, the

researcher demonstrated sensitivity to beliefs, habits, and lifestyles to people of different cultures and backgrounds.

### *Confidentiality*

With all participants, the issues of privacy, confidentiality, and anonymity were discussed during the informed consent process. Although the nature of the in-depth interviews excludes participant anonymity, all efforts were made to ensure confidentiality. Due to small sample sizes and thick descriptions, anonymity and confidentiality can be difficult to maintain in phenomenology research (Holloway & Wheeler, 1995; Speziale & Carpenter, 2007). To maintain confidentiality no names were attached to any of the methods of data collection. Instead code numbers were used on the demographic form, transcripts of the interviews, and in the researcher's journal. All information stored on a computer was protected with a password. All information including consent forms, audio taped data files, memory sticks, and coded field notes were kept in a locked cabinet inside the researcher's home, and one year after completion of the study, all data was completely destroyed.

A transcriptionist, the student researcher, and the thesis committee advisor were the only people who had access to the audio taped interviews. The only other individuals with access to the summarized transcribed interviews were the thesis committee members. All participants were assigned a pseudonym and any potential identifying information was altered to maintain confidentiality.

Finally, all participants were informed that the researcher was bound by PHIA and the Child and Family Services Act, which meant that the researcher was obliged to report any evidence of abuse (physical, emotional, sexual, and financial).

### *Risks and Benefits*

For this proposed research study, in addition to the risks discussed earlier, there were also potential benefits to sharing one's experience. Participants were given the opportunity to voice their thoughts and feelings of their lived experience with the ultimate aim of helping other families in similar situations. Participants were compensated with a twenty dollar honorarium for their time and participation in this study. Additionally, it was hoped that the information, knowledge, and understanding evolved from this study will enhance the lives of families living in a rural area while parenting a child with autism.

### Chapter Summary

A qualitative phenomenological study took place guided by the methodology of van Manen (1990). Data were gathered through in-depth semi-structured interviews, a demographic profile, and field notes. The research setting took place in mutually agreed locations and van Manen's human science method was used to analyze the generated data. In total, 26 families participated in the interviews, and all but one participant completed the follow-up interview. Data saturation was achieved through redundancy and the emergence of no new themes. Methodological rigor and ethical consideration were discussed with specific consideration of informed consent, anonymity, and confidentiality. The next chapter addresses the description of the sample and the findings of this study.



## Chapter V: Demographics and Findings

### Introduction

A description of the demographic profile, as well as the findings of this qualitative phenomenological study that explored the lived experience of rural families parenting a child with autism are presented in this chapter. Data collected from the demographic profile were summarized and described using descriptive methods. The second part of the chapter describes the lived experience through the eyes of parents and presents the essence of the experience and the meanings that rural parents attribute to parenting a child with autism.

### Description of the Participant Sample

Within this study, 28 parents from 26 families of 33 children with autism participated (see Table 2). Families were from all regions of Manitoba and lived between 15 and 800 kilometres away from the city of Winnipeg. In total, 26 interviews were completed; 22 were done by mothers alone, two were completed with both the mother and father present, one was completed by the father and one father was interviewed with his parents present. Participants ranged from 26 to 50 years old.

Table 2: Participant Characteristics (N=28)

Characteristic	Number (%)
<i>Age:</i>	
Age Range	26-50 years
Mean Age	36.5 years
<i>Marital Status:</i>	
Married	20 (76%)
Single	2 (8%)
Widowed	2 (8%)
Divorced	1 (4%)
Separated	1 (4%)
<i>Ethnicity:</i>	
Caucasian	22 (85%)
Metis/Status Indian	3 (11%)
Hispanic	1 (4%)
<i>Educational Level:</i>	
Some High School	1 (4%)
High School Diploma	5 (18%)
Some College	6 (21%)
College Degree	6 (21%)
Some University	1 (4%)
Bachelor's Degree	8 (28%)
Master's Degree	1 (4%)
<i>Occupation:</i>	
Homemaker	15 (53%)
Professional	6 (21%)
Clerical	2 (7%)
Labourer	1 (4%)
Management	2 (7%)
Retail	1 (4%)
Retired	1 (4%)

#### Description of the Participants' Children

Families had a range of one to five children with an average of 2.6 children per family. Thirty-three children within the 26 participating families were given the diagnosis

of autism spectrum disorder (see Table 3). Additionally, 13 children had co-morbid diagnoses including developmental delay, ADHD, Tourettes and ventricular tachycardia. The majority of the families had one child with autism while five families had two, and one participating family had three children diagnosed with autism. Twenty-one percent of the children were non-verbal while the remaining 79% were verbal or displayed some form of speech. Age at time of diagnosis varied with majority of the children diagnosed between the ages of 3-5.9 years old. Just under ten years ago, a diagnosis of autism prior to the age of four or five was rare, but through advances in research, an accurate diagnosis can be made by age two (Moore & Goodson, 2003). Thirty-three percent of the children involved in the study were diagnosed by the age two although majority were diagnosed after their second birthday. In a United Kingdom study by Howlin and Moore (1997), 93% of parents had concerns that something was wrong with their child by the child's third birthday, yet the average age of diagnosis in that study was over six years old. Furthermore, Mandell, Novak, and Zubritsky (2005) found that children who lived in a rural setting were diagnosed 0.4 years later than those living in an urban centre.

Table 3: Child Characteristics (N=33)

Characteristic	Number (%)
<i>Gender</i>	
Male	29 (88%)
Female	4 (12%)
<i>Age:</i>	
Age Range	2-23 years
Mean Age	8.8 years
0-5 years	13 (40%)
6-10 years	8 (24%)
11-15 years	8 (24%)
16-20 years	3 (9%)
>20 years	1 (3%)
<i>Diagnosis:</i>	
Autism	27 (82%)
PDD-NOS	5 (15%)
Asperger's	1 (3%)
<i>Age of Diagnosis:</i>	
Age Range	1.5-8 years
Mean Age	3.5 years
0-2 years	11 (33%)
2.1-4 years	15 (46%)
4.1-.6 years	4 (12%)
6.1-8 years	3 (9%)
<i>Treatment Program:</i>	
ABA	12 (36%)
RDI	1 (3%)
None	20 (61%)

Children's abilities varied in accordance to the activities of daily living.

Children's capabilities ranged from requiring no assistance to those requiring extensive assistance. Those that needed extensive assistance demanded much more support within their day to day living. While services varied, occupational therapy and speech therapy

were the predominate services obtained by families. For those families that received occupational and speech therapy, most received the service approximately once a month. Eleven children received funding for a full time ABA tutor, while six made use of a developmental worker. Within the school system, eight children received a full time educational assistance (EA) while another seven received a part time EA. One family used an RDI consultant, and four families obtained counselling services

### Findings

The next section focuses on the findings of this phenomenological study. The essence of making the invisible, visible emerged as what it is like to parent a child with autism while living in a rural setting. As the lived experience is at the heart of phenomenological research, the participants' words are included within the description to create a deeper understanding of the essence of their experience.

#### *Making the Invisible, Visible*

Making the invisible, visible emerged as the essential essence of parents' lived experiences of parenting a child with autism in a rural area. Parents shared that although autism was an invisible condition, they in fact made it visible in their constant battles to ensure that their child received the best quality of life within a community that supported and valued their child. Parents emphasized that the invisibility of autism made it difficult to obtain a diagnosis, gain valuable support and explain their child's behaviours.

They have no clue because 'C' looks perfectly normal. He walks. He talks. He doesn't have you know a stumble or a limp so you can't see a physical disability. (P17, 804-807)

He walks and talks perfectly fine. You can't see you know his disability and just because he has one um makes him just a little more different. (P17, 4450-4453)

Probably 99% of the people don't have a clue what it is, and you know with autism they don't look sick. (P10, 591-593)

Autism as a disability was hidden from members of the rural communities. If the negative characteristics of autism were seen (such as tantrums, meltdowns, yelling, disruptive behaviour, etc.), most people related it to bad parenting or to having an uncontrollable child. As one parent noted, "most people look at you and they just think he's a bad kid. Because he looks normal. He acts normal, well somewhat normal and, and talks normal" (P11, 1158-1168). Autism was invisible to the untrained eye yet visible in ways that people deemed as destructible and undesired. Furthermore, autism is a spectrum disorder that varies from child to child which is very unlike the Rain Man (see Theme: "He's not like the Rain Man") or what society views as autism.

Community members were often unaware of the difficulties that parents faced when parenting a child with autism. Due to the normal physical appearance of these children, these children often remained invisible which led to a lack of understanding of autism. Although their child with autism may have appeared normal, parents described the difficulties and challenges that their children faced on a daily basis including: over-stimulation and needing time to decompress; challenging new environments and the constant watch that parents must have on their child. Behavioural issues, tantrums, screaming, physical violence towards themselves and others were also common occurrences for children with autism. Difficulties in social settings and no concept of safety led to the need for vigilant parenting by participants. Parents also described their children's challenging ritualistic behaviour and picky eating habits. One parent expressed "different people have said he sure doesn't look autistic...He doesn't act autistic, but I said that's why it's called a spectrum. When you see him on a bad day then you'd see

autism” (P15, 1073-1084). Communication was an incredible challenge and the red flag for majority of the parents who knew something was different with their child.

Once a diagnosis of autism was received, parents were quick to inform family and friends although parents were cautious with those individuals who may not have been accepting of the child’s diagnosis of autism. As one parent described “some friends have been very open and accepting and you know go camping together and stuff like that, some friends are like back off, like it’s contagious or something and those are friends that I don’t want to be friends” (P9, 982-986). Although living rurally often meant that there was less of everything, most parents felt a sense of safety and support within their community.

Be very open. If you think your community is a good receptive community, like you should already know from living in a small community who the good people in your community are that are going to be a good benefit to you. (P6, 4674-4678)

In making the invisible, visible, parents described how they had to be the voice of their child. Parents had to overcome three barriers that hindered their ability to make autism visible: (1) he’s not the Rain Man; (2) society’s lack of knowledge and understanding; and (3) doing it on our own.

#### *He’s not the Rain Man*

To make autism visible, parents learned to define autism, discussed what autism entailed, and what the condition meant to them, their child, and their community. When asked about prior knowledge of autism, parents had an extremely limited understanding of this childhood disorder. Most parents made reference to the movie Rain Man (1988) starring Dustin Hoffman and Tom Cruise as their only connection to autism. As one parent stated, “he’s not Rain Man. That’s what I thought, because that’s all anybody

knows about autism” (P9, 573-578). He’s not the Rain Man was the reaction of most parents. Parents only knew the extremes of autism; the head banging, the rocking, and the lack of emotion. To parents, these signs and symptoms of autism were not associated with their child. Parents had difficulty relating their child to the character played by Dustin Hoffman, and as one parent stated, “I thought of Rain Man. Yeah like I mean so I thought well he’s not banging his head against the wall, he’s not, like really didn’t well he did rock a bit, he rocked in this sleep and that kind of thing” (P19, 413-417).

This limited and lack of knowledge of autism led to initial reactions of denial, fear, and shock. One parents described the diagnosis as “it was just numbing...the first thing I did was totally deny it. Cause I couldn’t figure out how can you sit and watch my kid for five minutes and, and give me a diagnosis that is so bizarre” (P22, 208-287). Parents started their journey in denial and confusion and had difficulty comprehending how their child who displayed many different characteristics than the Rain Man could still be diagnosed with the same disorder.

I was willing to entertain it but at the time I didn’t think it was that serious because it didn’t have, you know he makes eye contact and he smiles a lot and he like to be around people...at the time my knowledge of autism was so limited. (P19, 399-404)

Besides denial and confusion parents described a variety of other initial reactions. Parents grieved and described the diagnosis as a “death in your family. You still have that person here. But something dies” (P22, 1914-1920). Other parents mourned and stated “I just cried when she told me that” (P20, 146). While others were left devastated and felt like “your world falls apart...and what dreams you have for your child are, are gone” (P14, 242-254). Parents also displayed feelings of anger.



I was so angry and so insulted and when we left there I remember looking at him through the rear view cause we were driving away and he was just happy as a clam in his car seat and I'm thinking, I don't even know who you are, like how could that possibly be." (P13, 335-343)

Moreover, parents described feelings of being numb and overwhelmed, while other parents were scared and even terrified. Some families cried and some were disappointed. Eventually, all parents learned acceptance and as one parent explained it "I cried for about a week straight, I kind of got to that place where we were just going to work with it" (P2, 516-518). To reach this acceptance, parents had to begin to understand autism and had to learn from their child. From Internet to libraries to family, friends and their community, any information about autism was sought. As one parent described "and then within two days, I was at the library looking for information...I was like okay now I have to figure this out, I have to find out where we're going and where we're at and stuff" (P13, 3729-3738).

Persistent searching and researching enabled the autism with which their child was diagnosed to become visible to parents. Parents learned that autism was a spectrum and that children displayed an array of characteristics that were exhibited in multiple ways and discovered that "it's kind of like so he has autism and he has autism, but um they're totally like different" (P22, 3960-3961). With a thorough understanding of autism, parents were relieved to finally put a name to what they knew was atypical in their child and stated "it you know scared the, the heck out of us. But it, it was good that we, we had a, a name for it" (P25, 603-607). By comprehending autism, parents were able to alleviate their frustrations in exchange for reason. They understood autism and therefore, could better understand their child. They began to see the world through the eyes of their child which in turn brought them comfort and a sense of understanding. By

progressing through denial/fear of the diagnosis to acceptance, parents were able to eventually make the invisibleness of autism, visible to themselves and their community.

*Society's Lack of Knowledge and Understanding*

Parents articulated the lack of knowledge and understanding by their community and by society of what autism was, what was involved in caring for a child diagnosed with autism, and how autism affected everyday life of families. Parents had to learn to make this invisible neurological disorder visible to their surrounding environments including those within their community, the health care, and the educational systems.

Due to a lack of knowledge and understanding, families that parented a child with autism faced stigma of being different. Furthermore, parents that had more than one child diagnosed with autism faced increased stigma. To battle this stigma, parents taught their communities about autism and continuously advocated on their child's behalf. Within rural communities, the stigma that families experienced was more often due to the lack of understanding of autism rather than people being judgemental.

Lack of knowledge and that's the biggest thing like when I've gone up to those people or when we've held tele-health sessions or you know when I was on the radio and things and just the most common things that people just didn't know what it was. (P4, 2446-2450)

People became afraid of that which they did not know, and people "were scared of the autism" (P14, 2784). Participating parents became susceptible to premature judgements that were described by one participant as "people will make judgements. Most of their judgements were of ignorance. They don't even know what it is" (P15, 3541-3543). The perception of "bad parenting" was the first judgement facing families parenting a child with autism.

There were times where I just you know I wanted to say to people, like back off we know what's best. (P14, 626-628)

The things that would really frustrate me are just people that automatically assume that he's just a bad child if he's misbehaving in public. (P4, 2061-2064)

Because one cannot see autism, the child was expected to behave a certain way, if they differed, judgement was cast upon them and on their families. One mother stated "if I take him into the store now and he's seven and he's this big and he starts acting up then I'm the bad parent right" (P16, 2196-2198). Parents felt angry and disheartened by the actions of their community member at times despite their lack of malice. Although they acknowledged that it was society's lack of understanding which led to these judgements, the situation remained the same. One participant described this confusion "you get home and you're just destroyed because it replays in your mind and it is like why are people so ignorant. I know they don't understand but how do I make them understand" (P22, 3942-3945).

Making the invisible, visible was the way that parents were able to help their child become an accepted member of their community and enabled the best possible life for their child. Families found that the best strategy was to be open and honest and to share the diagnosis of their child with their community. The more that they talked about it, and the more they explained and taught the community about autism, the more support they received. Through this openness, one parent described their community as "it's more of a welcoming community now like we're finding that we're not being judged as much" (P4, 2087-2088). The majority of the school systems were a great source of support to participating families. One parent stated that "our school, I will say and I'll say it a million times over is phenomenal" (P15, 1944-1946). Besides a few families, the

majority of the parents found that rural schools had a willingness to learn and, with some persistence, were open to assisting families in creating the best possible learning environment for their child. By making autism visible, communities became more knowledgeable and understanding and instead of sending feelings of isolation and stigmatism, communities became a family of support that enabled families to provide the best quality of life for children diagnosed with autism.

*Doing it on our Own*

From diagnosis to treatment to advocating to the present time, doing it on our own emerged as a major theme in the essence of making the invisible, visible. Parents had to be the one to advocate for their child; they had to battle the health care system along with the educational system. To parents of this study, the system referred to the array of appropriate services including health care professionals and the educational settings that were designed to enable success in children with autism. Getting the required support and services only came through persistence and determination. Parents had to search out information, explore all options and constantly ask questions.

So I phoned everybody in the book and again waiting lists, where we lived were too far away. (P23, 871-873)

I applied and was denied, I was applied and denied, applied and denied...And I finally called there and I spoke to a very nice gentleman and I said what do I have to do [to receive an EA]. (P9, 1289-1293)

Moreover, parents had to teach, parent and spend hours of one on one time bringing their child out of the world they were enclosed in and into the world that surrounds each child. Parents never stopped advocating and always put their child first. In the end, they did their best through taking on multiple roles and constant battles while attempting to achieve the finite balance of life with autism.

From initial diagnosis, parents felt that they had to do it on their own and as one stated “I feel like there should be someone following him and I don’t know if they typically do, it’s kind of like they diagnose them and then you’re done” (P23, 3911-3917). Parents used their surrounding environment to seek out as much information as they could. Parents held onto everything they could get their hands on; the media, Internet, TV, books, close friends and relatives were all utilized. Following diagnosis, it was a search to find out what was offered for their child, what services were obtainable and how they were able to access them. Parents never stopped searching or leaning everything possible that would have a positive impact on their child’s life.

All parents received a diagnosis of autism for their child and were never seen again by the specialist, or even a paediatrician or rural physician.

That to me is frustrating because I’ve often used the analogy if you were diagnosed with cancer even through it would be the nurses that might give you the treatment and the radiation specialist who have you the radiation you’d still be followed up by your doctor and that just doesn’t seem to exist. (P15, 962-967)

I just thought I don’t know like how do I learn all this stuff. Where am I supposed to get it from? And who am I suppose to talk to? How come no one’s phoning me? Am I supposed to call someone? (P12, 2754-2761)

Parents stressed that even one follow-up appointment to the diagnosis would be extremely beneficial as most believed that “he gave me like all this information but it was kind of in riddles and when your kids just diagnosed you’re not really absorbing everything that they’re telling you” (P23, 619-622). Furthermore, multiple parents mentioned that “they should really have a, like after the diagnosis type of you know book or something” (P5, 2077-2078). Participating families were given a diagnosis of autism for their child and then were sent back to their rural community with no further contact or follow up care. Parents were thrown into the world of autism with limited knowledge

regarding the characteristics and demands of autism. Increased professional availability and at least one follow-up appointment would have provided comfort to these families.

Fortunately, families in this study were given a CSS worker who facilitated in connecting them with appropriate health care and educational services. Nonetheless, during this time, families still expressed feelings of isolation and as one parent described “you know I’m, I’m on this ship and I’m all alone” (P12, 2115-2116). Accessing all services and resources became the responsibility of the parents. Parents were on their own with educating themselves, seeking out services, hiring tutors and finding respite workers.

We were running this program, but all the tutors were gone at the end of the summer, so it was all up to me to start all over again by myself. (P18, 2852)

He told me right off the bat that he did not have anybody that could come out here and that if I wanted someone I’d probably have to do my best to find them. (P1, 896-898)

Because we lived so far north we were pretty much told there was nothing. (P4, 544-545)

Moreover, to being on their own, families had often the one and only child with autism and as one mother expressed, she did not think “that there’s one other kid in town with autism” (P10, 1283-1284).

Parents learned the needs of their child and how to set up a successful environment. They became experts in autism and experts on their child. They learned how to communicate and how to micromanage tasks. One mother describes this managing as “mom’s the one that drives them to Winnipeg all by herself to attend all the appointments and make all the appointments and take them to speech and run to *‘name of community’* and so I’m basically micromanaging everything” (P1, 859-863). Parents

learned that being rural residents meant that there were less available services and that “living in a rural area our population base for employees isn’t that great” (P1, 877-879). Parents started their own support groups and “I run a support group for autism, so I’m always talking about it” (P16, 2250). Parents learned to be direct in stating the needs for their child, and picked the battles that meant the most to them and their child. They had difficult days due to frequent challenges that came with raising a child with special needs.

When he was *threeish* there and I and I was ready to have a nervous breakdown in the office and I said I can’t keep doing this. It’s like banging my head against a wall and he just does what he wants to do anyway. (P15, 2439-2450)

And most days are good most you know but there are those times when you get weary, when you get tired. (P22, 3575-3577)

Like there’s just so much going on and I just can’t take it, I just can’t do another day of this. And then you do and then you take a deep breath and you laugh at yourself a little bit like we did a lot of laughing at ourselves. (P14, 3644-3651)

However, in the end, parents had a renewed sense of parenting, cherished the little things, laughed and learned patience and eventually accepted their child for all that they were and all that they could be.

#### Themes Supporting the Essence

Five themes supported the essence and ultimately represented the essential core of what defined parenting a child with autism in rural Manitoba: (1) using autism to enable; (2) lifelong advocating; (3) centering autism within the family; (4) the ups and downs of living rurally; and (5) a renewed sense of parenting. These themes described how parents were able to make autism visible within their supporting rural family (see Table 4).

Table 4: Summary of the Essence

## Making the Invisible, Visible

1. He's Not the Rain Man
2. Society's Lack of Knowledge and Understanding
3. Doing it on our own

## Themes and Supporting Categories

1. Using Autism to Enable
  - a. Playing the Autism Card
  - b. Dealing with the Barriers
2. Lifelong Advocating
  - a. Setting up an Environment for Success
  - b. Picking and Choosing your Battles
3. Centering Autism within the family
  - a. Multiple Roles
  - b. A focus on the Child's Needs
  - c. Finding Balance
  - d. Doing Everything we can
4. The Ups and Downs of Living Rurally
  - a. Less of Everything
  - b. Safety and Familiarity
  - c. A Family of Support
5. A Renewed Sense of Parenting
  - a. Cherishing the Little Things
  - b. The Importance of Humour and Patience
  - c. Acceptance and Preparation for the Future

*Using Autism to Enable*

Parents reinforced that they had no access to services without a diagnosis. As stated by one participant “for me it was just getting it official so that I could get the services” (P2, 420-421). Although a diagnosis was unsettling to parents, the diagnosis enabled parents to seek out services that helped them undertake the multiple challenges of parenting a child with autism. As one parent described their reaction to the diagnosis “and with the diagnosis came, um came ways to help her and a way to be proactive and I think anytime someone can feel proactive about a situation that they have no control over its, it's always good news” (P3, 630-637). Parents clarified that they did not use autism as an excuse or a reason for bad behaviour but rather to enable their child to do their very



best and enhance their quality of life. As one parent described “I don’t want her to use the whole autism thing as an excuse not to try to succeed to something” (P26, 1133-1135).

Parents expressed that in order to use autism to enable, they had to learn how to (a) play the autism card, and (b) deal with the barriers.

### *Playing the Autism Card*

Receiving a diagnosis meant access to a multitude of potential services and implementation of early intervention programs and strategies.

It is just a word. It is just a diagnosis. And it will help you get the supports that you need and so you need to forget about the word and live on the word and just use the supports that it’s going to give you. (P15, 2568-2576)

I got SL just to write me out a handwritten letter. One saying that you know her concerns about “S” being autism, autistic and stuff. And I used that to kind of get the jump to get her these developmental workers and stuff like that and uh, which is good because I didn’t receive the official letter till months after that. (P26, 382-395)

Parents made sure that the diagnosis did not act as a label, but rather enabled success in their child. One mother explained this balance, “so it’s really hard to find that balance...of getting him the resources he needs but not having this label attached to him that might hold him back unintentionally” (P4, 2117-2123).

Parents learned to play the autism card. As defined by a participant, “we have called it playing the autism card where, where he needs the help we want people to recognize he needs a little bit more time. But I’m not ready to just say hi this is my son “A” he’s autistic” (P4, 2107-2113). Majority of the time parents used this autism card to receive funding and expressed “but we had to do it [get a diagnosis] in order to get the funding” (P22, 472-473). Funding meant that their child received one on one support while attending day care or school. Obtaining a development worker or full-time EA was

often met with resistance and therefore, parents were forced to overcome barriers to achieve the services their child deserved and required. Parents learned how to play the autism card to receive the optimal resources for their child. One mother explained “he’s a flight risk when I need funding” (P16, 2841). Parents learned what to say and how to write it, “it was nice this guy told me exactly what they wanted...so that I could put that in there...it word it a certain way, so then we finally got approved for part-time funding” (P9, 1324-1335).

Parents graciously accepted the help from those people who wanted to help so as to give their child the best possible life.

I was talking to my mom and I was bawling, and I said you know like I don’t understand how they can label him this way, like this is going to change his life and she said, pull your head out of your ass, she says, you’ve got somebody offering help for him, how many kids never get a chance and they fall through the cracks, she says you’re crazy to turn these people away. (P8, 341-352)

Parents humbled themselves, accepted what was available and realized that accessing services and accepting support made a significant difference and overall, improved the quality of life of their child. As described by one mother, “cause help really does make a difference, like getting that speech pathologist makes the world of difference, cause it was less frustration for him, he could talk to people now” (P8, 3473-3476).

Unfortunately, accessing the services that were meant to enable children with autism to advance their development often remained inaccessible to parents due to barriers and resistance.

### *Dealing with the Barriers*

Accessing services and providing an appropriate environment for their child with autism was a challenging experience for parents. The system as described by parents

could be quite unsupportive at times requiring parents to overcome barriers and fight for what was required. One mother stated that “every day is a fight to educate and to get what the boys are entitled too” (P1, 3228-3229). Obtaining a diagnosis was the first step and this step usually occurred after a delayed waiting period. Parents frustrations were clear throughout the interviews “and when you’re a parent, when you know there’s something wrong with your kid you want to find out what it is as soon as you can so that you can deal with it” (P1, 337-340). Rural families experienced weeks to months of waiting, while those in Northern communities seemed to have the greatest wait. One parent in a Northern community described the difficulties in getting to see a developmental specialist, “it took like over, over a year to finally get there” (P12, 620). There were wait lists to see developmental specialists and wait lists for specific services. Parents learned that early intervention of strategies and programs individualized to the needs of the child was beneficial for improved prognosis. This delay in diagnosis caused much frustration, especially for parents who knew something was wrong, but who could not obtain services due to the lack of formal diagnosis.

Once a diagnosis was obtained, accessing the appropriate services brought its own barriers and challenges. Rural communities had less choice, fewer options and the further away a family lived, the longer they had to wait for support and services. Families living greater than four hours away from Winnipeg experienced a considerable reduction in available services and a dramatic decrease in professional support. Professional support was brought to these communities rather than these communities supporting their own professionals. One participant explains how “people that were flying up from Winnipeg every two to three months and they would spend an hour with my child. And I said that’s

not going to make any difference like this is ridiculous” (P4, 695-702). Families were forced to drive to different areas or in some instances were denied services due to unavailability. All rural communities were left with gaps as programs shut down for the summer and furthermore, positions went unfilled due to maternity leave or leave of absences.

His child development worker ‘N’ has just gone on maternity leave and they haven’t found anybody to replace her yet, they haven’t had anybody, I don’t think they’ve even had anybody apply. (P19, 1820-1824)

Our other speech therapist was on mat leave and she just came back so it seems like it’s going to get better but it’s still yeah being in a rural area it’s you know once or twice a month for an hour at a time so it’s not very much. (P10, 839-843)

Speech language pathologist, you know going on a mat leave so then there’s some gaps and then you get somebody different who...oh you know this is working out well and then that person ends up um she’s working out of a different community, so then we get a new graduate who just doesn’t seem to click with your kid as well as the other ones. (P25, 376-383)

Families had inconsistent services or were forced to travel to other communities or even to larger urban centres where they faced further wait lists, increased travel time and increased costs. Many families could not afford the cost of obtaining out of town services or had the time to arrange for these services and therefore, were left with none. Lack of collaboration between the array of professionals and within the school system was another barrier to receiving optimal support for their child. Treating autism took a multidisciplinary approach that was often lacking within the rural community. One parent stressed that “open-mindedness to accept the fact that there’s, it’s a multidisciplinary approach that needs to be taken” (P9, 2588-2590).

Going to a doctor’s or dentist appointment often meant driving to larger nearby city for the required professional which in turn, required more planning and more time.

One parent described the challenges in going to appointments, “even you know going to the paediatrician or going to the appointments in ‘*name of community*’ it does mean a day off work” (P24, 2493-2495). Parenting a child with autism took greater preparation and even if a service was available, extra time and scheduling was needed to benefit from the service. As described by one mother, “anytime I want to book him in ‘*name of community*’ I have to call a little bit in advance cause they like to book another staff in to look after him” (P19, 1755-1757). In addition, parents experienced moments when their child was not accepted and explained how “the preschool in our area does not want autistic children” (P6, 2684-2685) and “but ‘*name of community*’ doesn’t have any EA’s for kids with disabilities” (P7, 1366-1367). This lack of acceptance caused much distress to parents and these families were forced to have to search out alternative services in different communities.

Further barriers occurred due to the small population of rural communities, parents did not want to cause conflict with other community members and instead of advocating for the best environment for their child; some parents felt that they had to step back and accept the best they had at that moment.

Like that’s the thing out here you know, you know all these people so you don’t really want to tick them off by saying okay this is what I want you to do and I don’t know like and like I said it’s hard to know if they’re even going to listen...one of the girls kind of mentioned with these visual schedules and right now it is way over and above them and you know one of our workers just kind of like just almost laughed at her and said, like no it’s not going to be a good idea that’s over and above them...it’s hard when it’s a small town cause you can’t just get a new person easily. (P10, 1095-1099)

But there was one EA that wouldn’t, no I’m not going to come to your house and work. I don’t have to learn it...I don’t have to learn ABA, cause once he comes into the school we do our own thing, we do what we want, that is, you’re in the school now. (P6, 3522-3530)

Although some parents did not want to cause conflict, other parents pushed and insisted for the required needs of their child which led to confrontational incidents especially within the school system. Through these tough times, parents learned to “advocate positively...like don’t be adversarial...because you never know what you say today is not going to bite you, and, and understand too that you cannot expect everybody to be an expert” (P13, 4875-4885).

When approached with a challenge, parents created the best environment by doing the best they could with what they had. Parents became the spearhead of new ideas and services in their community. Parents learned to navigate the system and were not afraid to advocate for their child. Rural parents had to make the system work for them as they were usually the only family parenting a child with autism or were the first family in their community to have a child diagnosed with autism. Parents advised rural families to “utilize what little you have here but use it to your advantage” (P22, 3744-3745). In addition to navigating the system, northern families had to make up their own system as there were none and in turn, enabled other families whose child was newly diagnosed with autism to benefit from the system as well. As described by a parent in a Northern community stated “we have no services, we have no resources, you know we’re just kind of learning as we go” (P12, 2406-2408). Parents worked around some barriers while taking a stronger stance on others. Parents became insistent on things, some became “the squeaky wheel” (P14, 3386) while others “jumped through hoops” to get what their child deserved; “I already knew that you had to jump through a lot of hoops in order for your for your child to get educate sufficiently” (P17, 2091-2093). Parents learned to fight for what their child requires and attend to things as they came their way. One mother stated

“like whatever comes my way comes, and if it’s good or bad I still deal with it” (P20, 1767-1768). In the end, parents overcame multiple barriers to provide the best environment possible to enable their child to reach their full potential.

### *Lifelong Advocating*

To make the invisibility of autism visible it was up the parents to advocate for their child.

You really have to be the biggest advocate for your kids so you have to be the one just pushing things and asking for things and just and really making your voice heard I think cause that’s the way I think you get more results. (P2, 1098-1102)

I just know that I do it and I have to do it because I’m the only advocate for those two and I’m the only thing that keeps the whole family unit together because as crazy as it is I understand each of them and the way they think and the way that they interact. (P17, 3237-3241)

Through lifelong advocating, parents enabled their child to become successful. From diagnosis to services to future planning, these parents were self-motivators and never stopped advocating on their child’s behalf.

Overcoming the denial/grieving stage of diagnosis allowed parents to take things into their own hands and “when I finally got over that and I just woke up one day and I just said it’s me or nothing so what’s it going to be and I just lay there and I go okay well I guess it’s me” (P22, 1410-1413). Parents described how arriving at this decision was not a choice; rather it was something that had to be done. One parent expressed “be willing to be your child’s best advocate I mean if you don’t do it nobody else is going to” (P4, 3548-3550). Parents started support groups, web pages and newsletters to provide greater understanding about autism; one mother stated “I have a webpage and I send out newsletters every, every month” (P16, 3382-3383). Parents wanted people in their

community to understand and know autism and this led to presentations within the school to teach children what it felt like to have autism.

So I went to the school and I asked the team I said I need to get the kids to understand what autism feels like. So myself, Children's Special Services and the speech path we put a presentation together...and we went in and we taught the kids from K to grade six of what autism might feel like. (P22, 1425)

Additionally, parents advocated at the university level and one mother even “phoned the University of Manitoba after and I said my son was just diagnosed with this and I was a nursing student there, I don't remember learning about autism and it really would have benefitted me personally” (P6, 4915-4919) in order to make autism visible.

Parents advised other parents that “you have to be very strong...and you have to be a good advocate” (P14, 3367-3371) and stated that “how to advocate for your child was one of the most important lessons I've ever had out of any educational opportunity in my life” (P6, 2475-2477). Parents employed two strategies to advocate for their child: (a) setting up an environment for success, and (b) picking and choosing your battles. These strategies addressed how parents took things into their own hands to see the visibility of the invisible condition and therefore, were able to provide the best possible quality of life for their child.

#### *Setting up an Environment for Success*

Although there is no cure for autism, parents encouraged their child to live life to their full potential. Parents believed that their child deserved everything that every other child received and given the right environment, they had the ability to thrive. As parents reinforced that they understood their child the best, they made sure to advocate for an environment that enabled success rather than failure based on their child's needs. Parents described that “it was a lot of trial and error at the beginning” (P5, 2646-2647) as they



learned what worked and did not work for their child. Parents explained the benefits of visual schedules and one parent shared “one thing that I guess we’re going to work on together is doing what they call a visual schedule...like a picture of brushing your teeth and this is what we do in the morning” (P26, 1398-1407). Additionally, structure and social stories as described by a participant “so we had to do a lot, a lot of talking and counselling and using social stories” (P17, 826-827) were also beneficial. These strategies helped their child with autism to know what to expect, created routine and prepared them for upcoming events in order to avoid meltdowns and failure.

Parents began to organize their day according to the needs of their child and described how “we sort of plan things for either mornings or afternoon cause we know evenings aren’t, aren’t great for ‘M’ so we have to tailor things that way” (P25, 1775-1778). They rearranged their home to initiate learning. One parent shared “so far us to get him engaged in something, we literally left toys all over the floor all the time because he would have to fall over top of it before he’d notice” (P13, 769-771). As described by one mother, they turned bedrooms into classrooms and “the master bedroom was set up with that and um the linoleum on top of the floor...and you had shelves with toys on the top of the shelves so if he wanted anything he had to point or gesture” (P18, 1853-1859). Basements turned into play rooms “like downstairs in suppose to be a rec room and that’s his room...I’ve got you know the BOSU ball for balance. I’ve got the small trampoline; I’ve made him a big swing” (P11, 602-609). Parents built play structures outside to initiate neighbouring children to come over to enable social interaction and built obstacle courses inside. Parents were open to learning, open to rearranging and explained that “she would actually come to our house because we lived across the street so she’d actually

come and work with him in our environment to help me set up my environment for him” (P23, 321). Parents were open to the preparation and as described by one participant “it’s just kind of that prep that setting, setting things up to, to have him succeed” (P15, 1890-1891).

Besides their own environment, parents had to prepare for the unknown, prepare for the unexpected and prepare for the future.

We started fundraising for “D” when he was probably sixteen and we had like a social and we had a perogy drive and we had all kinds of different fundraisers...and we fundraised about thirty thousand dollars and we bought a house for him in “*name of town.*” (P14, 982-997)

Parents had to plan not just for today but also to anticipate future needs. They spent hours preparing their child for upcoming appointments or special events. One parent shared “whenever we have an event coming up or something that’s different I start preparing them” (P1, 2633) and many parents described how they would assist their child through new situations, “I’ve always walked “D” through exactly what’s going to happen” (P14, 3283). As another parent explained it, “it’s not that we don’t take them anywhere, it’s that it takes a lot of preparation to get ready to do it” (P1, 3059). Even the simple task of going to the dentist took time and preparation. One mother spoke of the time and work that went into preparing for a dentist appointment, it “took a lot of any books that I can find on you know Elmo going to a dentist, or Elmo going to the doctor...or any character that they were interested in at the time so that you can pre-teach going to the dentist” (P1, 2970-2977). Each family was able to describe multiple situations that took extra preparation and teaching such as transitioning to a new school, “the liaison worker from the middle years school made arrangements with the resource teacher at the high school and they took ‘C’ over on a day and it was ‘C’s’ special day” (P17, 2468-2471), riding

the bus, “the bus driver would do her last stop, she came back to the school for fifteen minutes, they put “H” back on the bus and they worked it for fifteen minutes and, and she did it, she learnt it and we were all like yay” (P3, 1418-1422), or simply singing “Oh Canada” with classmates at school, “we pulled him out and we taught him Oh Canada and we gradually got him closer and closer to the door...and then you know in grade seven he’s the only kid singing Oh Canada” (P18, 1142-1150).

Parents believed that a child with autism failed due to lack of preparation or an inappropriate environment.

We have to try, try and work together and, and uh you know we do um things you know we organize things around “M”...because it’s like if we know you know we’re just setting up “M” for um an unsuccessful even that’s going to be bad for everybody. (P25, 2383-2391)

Furthermore, failure and meltdowns were also due to poor planning and preparation or missed signs that their child tried to tell them.

Bad behaviour will happen if this is not structured and safe and for him predictability is safety so you have to do it this way so that you don’t get this garbage over here and it’s not, you know when he comes home we go by the same methods, so its’ not like we’re undoing everything. (P13, 3085-3090)

He will warn you when he gets really angry just with his facial expression he gets really angry and he you know clenches his teeth and clenches his hands...and he kind of lunges at you and so he will warn you before he strikes so to speak...um which is not very often but when he does I mean in the back of your mind you’re thinking well we all deserve it he warns us, and then we don’t back off. (P14, 1203-1217)

Parents learned when to push and when to stop “if things aren’t going well we don’t just keep saying don’t do that, don’t do that. It’s like a one two three rule...and if you’ve done it you know three times then we just would pick up and go” (P15, 509-516) and never placed blame upon the child for an incident that could have been prevented.

It's because he's been put into a situation that was very over stimulating for a really long time um we have to say to ourselves we should have known that was coming...you know we can't set him up for that kind of disaster that failure. (P15, 1874-1882)

Parents spent time preparing, being proactive and “protective of not wanting something bad to happen and wanting to be really rigid with his schedule cause if you weren't and it was *wishy washy* it was like all hell broke loose” (P15, 2915-2918). Overall, parents learned how to create a successful environment for their child. Parents believed that children diagnosed with autism need more guidance and structure but were entitled to an education within a learning environment that enabled success. Although there were challenges that occurred, parents did what they could to give their child the best quality of life while living with autism.

#### *Picking and Choosing your Battles*

When advocating for their child, parents learned that it was their responsibility to be the voice of their child and sometimes their voice was met with resistance.

The children do not run the show and when you have a child with a disability if you, if you think the whole world can accommodate them then do whatever it is you feel is right, but since you know that the world will not ever accommodate their quirky behaviours or all of their little finicky things and all stuff then it's your job to make them socially acceptable. (P13, 4850-4856)

Ultimately, it came down to picking and choosing the battles that were most important to parents, “there will always be things we let slide that we're just not up for the fight today” (P13, 2834-2835). Parents learned to be the best advocator and set up a successful environment but also realized that “you can advocate for your child and do what's best, there are things you're going to have to give up along the way so find out what's important and go after that goal” (P13, 4890). Parents encouraged other parents to “do your research...and don't take no for an answer” (P4, 3508-3512). Parents did not take the

laid back approach to life with autism, instead they fought for all that was required and if “you want something you go after it and you do it and until you’re happy with the result and carry on” (P13, 4867-4869). Parents learned when to challenge, when to let go and to “make your own decisions; be secure and confident in your decisions” (P9, 2437-2438).

In the end there were some issues that were more important and just worth fighting for. It was those issues that meant the most to families kept them pushing, insisting and fighting. From diagnosis to ensuring the best quality of life for their child, parents never stopped fighting, never stopped advocating or stopped pushing their child to do better, to want more and to do the best they could in every situation. Parents became a crusader for their child’s needs and often had to convince the health care and educational systems that it was the best interest of the child that was most important rather than the best interest of the system or the parent.

It’s been just a huge learning curve teaching people we’re not here for us. We’re here for that person so whatever it is that you think that you’re adding to it you know put your attitudes aside and let’s, let’s think about the kid. (P22, 1191-1195)

Parents understood that they were their child’s expert and that although people could make recommendations and suggestions, ultimately, the parent had to make the best decision.

Living in a rural community often meant less services and less choices but to parents in this study, this drawback enabled parents to search and fight for what their child deserved.

Your services are going to be limited and you’re going to have to fight for them...fight for letting them know why your kid deserves that service over somebody else’s kid. (P16, 3854-3860)

Just because you’re not in the center where most of the facilities might be. That doesn’t mean you can’t get those resources...you know again just reaching out to

the people that are there and finding out and jumping ahead of everybody. If there's a wait list find out why...you know if um if there isn't a support group start one. (P4, 3517-3531)

Parents learned to be persistent.

So I phoned and I phoned once a day and then I started phoning twice a day, got any cancellations...no, hi it's the afternoon now got any cancellations...no, okay phone you tomorrow, got any cancellations, after two weeks of doing that I went in the next day, I, I still tell parents to do that. (P14, 1882-1887)

Parents learned to take on new responsibilities and roles; "I just tell people don't be scared, just call, even if you're calling the wrong number, somebody will give you something, somewhere" (P5, 2128-2130). Although parents advocated for fighting, they did not advocate for aggression or a combative nature, parents believed that one must "be willing to you know to fight for it and that doesn't mean being an angry person you know and being you know aggressive...but just be willing to be your child's best advocate I mean if you don't do it nobody else is going to" (P4, 3542-3550) and recommended that parents fight "in the contest of what works for your family to do it well and to know that when you go to bed at night you're doing it well" (P13, 4860-4862). Overall, parents fought to provide their child with the best quality of life in the most successful learning environment and believed that "when somebody needs something that would dramatically improve their quality of life you do it" (P4, 2905-2907).

### *Centering Autism within the Family*

To parents in this study, the diagnosis of autism became the focus of their family and their life. Parents described how their life slowly began to revolve around the child with autism for autism was a daily challenge. It became so normalized that families did not even realize the daily things that they did in order for their child to function. Every decision was affected by autism and it affected every choice that families made. From

morning awakening until the time that they went to bed, autism was present. Parents could not hide from it, nor could ignore the autism in their child. In the end, participants were satisfied that they did the best they could with what they had. Through all the battles and challenges, parents went to sleep each night knowing that they did all that they could. If there was something else to be done, parents woke up the next morning with a renewed sense of determination and began the day with a purpose of providing the best for their child. While parenting a child with autism, autism became centered within the family and parenting now included: (a) multiple roles, (b) a focus on their child's needs, (c) finding a balance, and (d) doing everything we can.

### *Multiple Roles*

To parents in this study, a child with autism had more, needed more and required more. They had more difficulties and challenges; they needed more direction, repetition and supervision and required more support. Parents played every role for their child. When fulfilling the day to day needs of their children, participants acquired multiple roles within their home and community. Parents became advocator, mother, father, teacher, tutor, and primary caregiver.

Do you know how much energy it takes and patience and so anyhow um when I started making my list I'd come up with a few little ideas and then a couple more and then I started realizing that you know what everything. I help him with his hygiene. I have to remind him when he has to have a bath. I have to wash his hair *cause* he has excessive dandruff...and uh so that more I started thinking about taking a day and dissecting it in what I do I realize that as much as things get done on daily basis it's a lot and I just do it. (P17, 3099-3123)

Then I would whisper in his ear, okay you know what the song's almost done, as soon as the songs done we're all going to clap and then I would take his hands and I would clap too...and he'd be screaming and clapping at the same time, it was so cute. (P14, 2284-2292)

I was a sub in the classroom a lot of that time too because they had an aid but I didn't I was the one training here and they let me come in to train her. (P18, 3743-3746)

For families involved with ABA, parents had to do the searching, to train the candidates and if necessary to teach ABA themselves until the position was fulfilled. As described by one parent "so I pretty much took it upon myself to learn ABA. I said well I'm not sitting around and waiting until you know my kid's in a hole here, he's like in the dark ages, you know I've got to pull him out somehow" (P5, 511-518). Parents became a teacher and spent many one on one hours with their child. Other parents volunteered at daycare and in the classroom. Parents learned how to teach and understand their child. They learned how to play music instruments to teach their children. As described by one mother "because I taught him piano...with the very little that I know. You get the primary books and they're self-explanatory. You can so, so I knew, I knew how to teach him" (P18, 1196-1202). They did things on a daily basis without even realizing how much or what they did.

Participants learned to cut hair because of the difficulty of having a child with autism sit through a haircut with strangers and explained that "yeah, I have to [cut hair] because its, it's too much hassle taking them to someone else's place and having them cry and scream and tantrum" (P1, 2937-2939). Parents became coaches "and I was coaching and everything, so it was easier. You just have to just, I've put myself out there and just say you know what, he's got special needs" (P11, 1147-1149) and had to be vigilant as they explained that "it's hard keeping track, you have to be hyper-vigilant at all times for three kids who are prone to wandering away" (P1, 1284-1286).



Furthermore, multiple participants were employed full or part time, “did I mention that I have three jobs and, and a mom” (P9, 2153), and many ended up changing their occupation to best suit the needs of the child.

‘S’ worked three jobs so that I could afford to stay home because I was working casual in the hospital but it’s kind of stressful going to work when you’re only there six days a month and you don’t really get the rhythm of what’s going on. (P23, 1279-1284)

When ‘D’ was about six months old I realized that I probably would never be able to have a job outside the home, so I was trying to think of what I could do from home, so I did take a medical transcription course. (P1, 2053-2057)

Moreover, some parents had to quit their jobs to care for their child with autism.

Changing or quitting jobs was a difficult decision when the cost of accessing services was increasing in a time of potentially decreasing income. However, if parents continued to work, many rearranged their work schedule to provide for their child and family and as one parent explained “leading up to age two I worked, I chose to work exclusively nights so that I could be home during the day” (P13, 657-659). Parents arranged schedules to best suit the needs of the child and still managed to save time for research and learning about autism. Doing “the research, and doing the everyday thing with your kids, and micromanaging their appointments and all of the tutors and making sure you have a respite worker and getting a respite worker” (P1, 3382-3385).

Besides managing their own families, parents spent time looking out for the needs of other families that had children with autism and other disabilities “and I have since joined the Board to make sure that children with special needs are included and that they get everything that they should be entitled to” (P1, 1466-1468). Participants acted as primary caregivers, disciplinarians and as explained by one mother “some days I’m a disciplinarian and other days it is like okay is it going to matter next year or next week”

(P22, 3636-3638) while others were referees. There were days that they did not want to get out of bed and “there’s been times just even recently I spent the day in bed. I didn’t want to do anything. I just get overwhelmed with everything and I spend the day in bed” (P18, 5054-5057). However, somehow parents still managed to maintain balance and continue on. Although at times parents struggled with the multiple roles, the success seen in their child was their greatest reward. It was through their hard work and persistence that enabled success. In the end, parents attempted to bring their child out of their own world and into the world of their community. They strived to enable their child success with everything and they never stopped making the invisible, visible.

#### *A Focus on the Child’s Needs*

Autism was a reminder to parents that being a parent was the most important role that they would ever have in their life. As such, parents put even more energy into ensuring their children’s needs were met, while putting their own needs aside. Parents took on the “it all revolves around the kids” (P6, 4430) approach. Parents own necessities were placed aside on multiple occasions due to excessive attention and time spent with their child with autism. Parents dedicated their life to their children, which led to increased challenges such as mental disorders, days of nearly breaking and marriage breakdowns. Parents sacrificed a part of themselves and a part of their other children to provide for their child with autism. Similar to feelings of doing everything on their own, parents of rural communities felt overwhelmed with the day to day tasks of parenting a child with autism. As one parent explained “I cook. I clean. I get everything ready for the kids to come home so that I can be with them and I’ve lost my own identity because the

boys are so needy” (P22, 3501-3504). Due to the lack of support, living in a rural area only added to the feelings of having to do it all on their own.

There were lots of dark moments when I remember like shutting my bedroom door and crying and thinking how, like how’s this ever going to get better...like there’s just so much going on and I just can’t take it, I just can’t do another day of this...and they you do and they you take a deep breath and you laugh at yourself a little bit like we did a lot of laughing at ourselves. (P14, 3637-3651)

You start closing yourself off from the world, the community and it’s like nobody understands, nobody wants to understand um *yeaa* it just gets very lonely. (P22, 1935-1938)

Parents felt that their own emotional needs were not attended to and due to the rural environment they had nowhere to turn or no one to talk to and nobody to truly understand what it was like to live with autism.

I probably really needed was just someone to sit and cry with, but well I couldn’t quite admit to that so I said I want to talk to someone who knows about autism...so they referred me to a child psychiatrist in “*name of community*” who also told me she had very little experience working with kids with autism. (P15, 2797-2811)

It’s horrible and when you have nobody there to sit and rub your back or let you cry or let you complain why is he doing this or he put his foot through the wall...I went looking and I phoned my guy from Children’s Special Services and I said I would like to see a mental health worker, a counsellor, a therapist that specializes in understanding uh parenting with special needs and there is nobody. (P22, 1924-1954)

Even the neighbour down the street, I’ll be saying something, and she’s oh yeah you know it’s the same with her kid, no it’s really, it’s really not. You don’t need to win this one, unless you’re wiping poop off the walls at this very moment let me win this one. (P16, 2376-2384)

If a community was fortunate to have a parent support group, making the time to attend and find respite workers proved to be quite difficult. One parent explained “that’s why the parents, you know parent support...so far down the list, nobody can meet because you’re doing everything for these kids...so that’s why it makes it really hard I think, the

parents kind of come in last in that” (P6, 2398-2414). Parents expressed that all of their energy was spent on their children that led to exhaustion and burning out.

With the time that it takes to take care of your autistic child, any little extra time that you have is put on any of the other children in that family...so to have time where it’s actually parent time to get together and learn things, that is so far down the list. (P6, 2133-2141)

You know we can’t leave ‘M’ with so and so because they’re not going to be able to handle it or you know so then you end up just doing it yourself. (P25, 1067-1070)

I found that my husband and I would burnout and the worst thing was you know you’d go to a safe zone to vent like your, your parents or something...you know they would always say things like well he’s never any trouble when he’s here and that would just add to your stress. (P14, 1276-1295).

Parents recommended to “try and take breaks” (P25, 2457) and use whatever respite that was available, “in fact honestly until we started getting respite services we never went out” (P8, 2296-2297). Parents that had more than one child with autism faced increased difficulties with finding respite workers and tutors and therefore, faced increased challenges with achieving balance. When it got extremely difficult, participants realized that they had to take time to themselves, “when you have so many other issues pressing on you that it’s really hard to focus on each and that’s important *cause* it takes a lot to hold a family together” (P8, 4637-4640). Overall, parents parented by putting their own needs aside by fulfilling the needs of their child first. Over time, parents learned how to take appropriate breaks and seek out available support and strive for balance within the family.

### *Finding Balance*

While parenting a child with autism, finding a balance was fundamental to parents’ survival. Although parents put their own needs aside, in turn, they stressed the

importance of striving for balance within the family. Parents spoke of the difficulties of finding balance, “but it’s finding balance and it’s hard” (P23, 4286) and sometimes how they ended up with a different balance than previously thought. As described by one father “finding balances for things have always been tricky and I just think finding the balance between family and work is I don’t know too stressful for me right now I guess. I’d rather just focus on being a dad and going the best I can to being a dad” (P26, 769-773). Parents quickly realized that putting their own needs aside had more detrimental effects than good.

Initially um I didn’t worry about getting, getting exercise for myself, it’s like you know I’ve got all this stuff to do with the kids and, and in the last couple of years that’s really, that’s switched over cause I’m like if I don’t, if I don’t get out there and, an you know get some of the stress off with the exercise and get, you know get some weight control stuff going on then I’m not going to be good to anybody, so yeah I had to really um smarten up about that, and, and we can all convince ourselves oh there’s no time for this but you know you figure it out, you make time so. (P25, 1737-1748)

Spending time on themselves enabled parents to best provide to for their family. As one mother shared “getting the panic attack changed that because I had to start back into exercising and, and looking after myself again in order to help my kids” (P18, 4495-4497). Parents learned to find the balance between the needs of their children and the needs of themselves.

For families where the couple was married, finding the balance between family and marriage was extremely important and parents often to had lean on each other in times of stress.

It’s like if we don’t stick together um because you do have to make a conscious effort and it’s not easy, it’s very very hard and yeah um it would be easier some days to just run for the hills, but at the, you know his is, this is ‘M’ and he’s, he’s ours and we’re going to try and do our best but it’s like we need, we need to be together to do this. (P25, 2787-2794)

We had some stressful times um but in the long run it really brought us closer together...like when we kind of went through that phase where it just we didn't know what was going on. We started to just really lean on each other. (P4, 2659-2666)

Parents explained that to maintain balance they had to talk and help each other out along the way.

My husband at the time worked in town so he would come home at lunch and often I would be waiting outside cause I'd be, I just need to go over to the store, or I need to go get the mail. (P13, 2286-2289)

It's just a matter of supporting each other, we have bad, you know one of us will have a bad day and the other one will pick up the slack. (P16, 2328-2330)

Furthermore, parents learned when they needed a break and as one participant explained, "I need that time to myself...and it helps my self-awareness so that I'm not just reacting to things throughout my day with the kids...So I actually have time, I reflect on my words and my behaviour before I do it" (P9, 2087-2097). Parents took all help and respite whenever it was available.

Whenever somebody did offer like his aunt to take them, it was...yeah, go and you know try, try to take that time and really you know sleep or do something for yourself and I find I like to read or something so I'd try and make time for that all the time whether I'm tired or not just to get my mind off of it. (P10, 571-580)

Parents learned to make their own time and space for themselves which often led to getting up early, having a bedtime routine, and making time for each other.

We built a big addition on our house which is our bedroom but it's sort of styled after a hotel room...so it's huge, it's a suite and it's got a huge bathroom and a big walk-in closet, uh double French doors that you can lock...and we would definitely retreat to that room...just to have a break. (P14, 3017-3039)

I've always made sure I have really good bedtimes routines, *cause* at least if I'm kind of running and crazy all day I at least have a couple of hours in the evening to myself. (P19, 2247-2250)

Although there were times that parents struggled, they learned to strive for and find balance.

I'm not going to lie it was hard for sure it was hard but I did it, I did it all by myself. (P20, 1133-1134)

I don't know how I do it. I really don't. I can't tell you what my secret is because I have three men that live in this house who all have special needs. (P17, 3151-3153)

To parents of this study, taking time to learn about autism, to seek out available support from within the community and receiving this support was crucial to maintaining balance and therefore, maintaining sanity.

### *Doing Everything we Can*

At the end of the day, parents were satisfied that they used their resources and strengths to their potential. Parents were determined that they were “going to do the best I can tomorrow and, and just see what happens and uh everything's kind of got a way of working themselves out” (P26, 890-892). Although living rurally meant that they did not have access to certain services and resources, parents learned to use all that they had to their advantage and as one parent shared that one had to “make your own resources...I mean everything's what you make it” (P23, 4250-4255). Parents made the best of every situation. They did whatever they could, whenever they could, with whatever they had. From the moment after diagnosis, parents began doing all that they could. As explained by one parent, “but it didn't last very long that whole being devastated, it, it I mean you have a choice right you can, you can sit and cry about it or you can try to do everything you possibly can” (P19, 791-794). Parents immersed themselves with autism and autism became the focus of their family. For some, autism was their life. They were entwined so deeply that they did not know or understand life without it and this was shown by one

mother “that’s all I know, so for me it’s just that was just like, that’s just what we did” (P2, 291-292).

Families took on the “try anything” approach to autism and believed that to have the best success, everything should be attempted. They learned to try new things and undertook anything that may have positively impacted their child’s life. As described by one parent, “I just want to make sure we try, we try everything and rule out what doesn’t work, you know what I mean” (P19, 601-604). For participants, life was about trial and error and finding the best fit for their child. Parents did not always have the answers but they never gave up. Parents that had a non-verbal child with autism faced increased difficulties with communication but adjusted well. Parents adapted to their child and learned how to read the non-verbal cues while some resorted to devices such as a Picture Exchange Communication System (PECS) or communication board. In the end, all families went through difficulties and challenges. If something did not work out, parents would try something different, but overall, they never stopped trying; they never stopped wondering and never stopped looking for something better to enrich their child’s life.

Parents wanted to do everything they could to improve their child’s life. Some parents hired their own consultants, “we got the funding for ABA...and we hired a consultant out of province” (P3, 433-437) and many were the first family in their community to run ABA therapy. Parents tried medication, biomedical models, and diet changes including gluten, casein or dye free diets. Others looked into Greenspan’s Floor time Model and RDI therapy as potential treatment options for their child’s autism. Families drove to larger cities and urban centres to access services and find activities for their child to participate. Parents involved their children in speech, occupational, and



physical therapy. As one parent put it; “I’d like to think that I’ve tried everything I could” (P9, 2450-2451). Parents attempted to do “the best, best we could” (P5, 55), never stopped looking for new ideas and believed that “every day is a learning experience and I’m always seeking out information because I guess you can say I’m self-conscious about am I doing the right thing for my kids” (P1, 3336-3339). Although parents wanted to do everything they could, they knew it was an ongoing challenge with many obstacles.

I wasn’t naïve to think that I was going to heal my child. But I was on a mission to get him what he needed if that meant we moved, if that meant I was knocking on doors I was going to do that. (P4, 603-606)

They strived for the perfect fit of services and success in their child. They made autism visible and in turn, tried to give their child the greatest quality of life.

#### *The Ups and Downs of Living Rurally*

Living in a rural community proved to have both positive and negative attributes for families parenting a child with autism. The greatest disadvantage to smaller rural communities was that there was less of everything; less amenities, less services, less professionals, less resources, and less choices. If a service happened to be available, there was less choice of options. Although respite funding was available, majority of this money went unused as finding respite workers was found to be extremely difficult. From lack of resources, lack of experienced health care professionals to lack of educational tools, families felt isolated in terms of services but not in terms of the support received by the community. When describing the ups and downs of living rurally, parents explained that the rural community had (a) less of everything, (b) safety and familiarity, and (c) a family of support.

*Less of Everything*

Participating families felt that in terms of autism, rural communities had less of everything and lacked amenities, services, and resources. Communities lacked variety and choice of services and “yeah there is a lack of services and education” (P23, 4061-4062). They lacked professional support and ways to cope with autism. They lacked access to mental health services and professionals who were able to work with children with autism. Rural communities lacked diversity and had fewer amenities from which to choose. They lacked the education to train people and struggled with obtaining and retaining qualified professionals. Summer programming was often cancelled and activities for children to participate in were limited. Moreover, technology was not used to its full potential. Parents found that communities had the basic essentials. As stated by one participant, “there’s the early school, the middle school and a high school and that’s it” (P18, 4787-4788). They were assigned one CSS worker and if needed and available, one speech, OT and PT worker. Unfortunately, if the parent deemed the professional not to be the best or most appropriate fit, parents had no one else to turn to and “now you’re kind of stuck with not necessarily the most experienced people, um and if you don’t like your OT or you don’t like your speech pathologist from the hospital...you’re left with no one” (P16, 3076-3088). Furthermore, difficulties arose when a service became unavailable or if parents wanted other choices. Parents were forced to wait or seek alternative services which included driving long distances and paying for private services that would normally be covered. One participant stated “I had been increasingly frustrated with the lack of initiative and the lack of experience um with what the

government offered...we go see a private speech pathologist in Winnipeg” (P16, 1073-1080).

Difficulties also arose when a service was unavailable due to unfilled positions or lack of professionals. As rural communities had a smaller population pool, there was a limited amount of choices to fill the needed positions. Moreover, small towns had difficulty attracting health care professionals and other professionals to their communities. One parent described this difficulty as “that’s the problem with ‘*name of community*’ is that it’s very hard to attract and retain professionals” (P1, 640-641) or quality of professionals, “as far as the resources it is a little frustrating that you don’t get the same type of quality of professional people in the rural area as you do in the city” (P17, 3531-3534). As well, families had to deal with professionals that lacked experience. Parents expressed that “you have one choice. And the choice, and like I live, I live rural so but you’re not going to necessarily attract the most experienced people” (P16, 760-7620). Parents also described situations in which there was one professional covering two or more areas and therefore, services were cut back immensely or families were forced to drive to another community or were left with no one to obtain the much needed service.

He was covering her whole area and he said you know I’m basically just putting out fires here. If you need me I’ll be here and he was very good about that, but I thought to myself yikes I bet you your area is big enough never mind cover two of them. (P15, 2866-2870)

I think because ‘*name of community*’ is suppose to have a speech path and she didn’t, she was overloaded and couldn’t get in extra people here so if we wanted therapy we had to go there. (P1, 613-616)

What I have found very difficult with the Special Services is that they don’t have respite workers cause now ‘C’ have been without one for over a year...and he really, really could use one. (P17, 2576-2582)

They'll have someone in the resource person's position and then oh that person has moved on to another job and then they get somebody who really doesn't seem to know how to do the job as well as the one who left and you're really starting from less than zero. (P25, 2539-2544)

Fortunately, if the health care professional was appropriate, the service enabled success in the child, parents were happy and the child benefited the greatest.

The school system was another area of concern for some families. Although most families described the excellent support provided by the school system, some families faced difficulties and had multiple challenges due to living rurally. Families only had one choice in schools but learned to use the school system to their advantage. Parents also reported that school systems had their own difficulties with retaining and recruiting health care professionals. As stated by a parent "the speech path used to but now she's on mat leave. The school psychologist used to be there but there is no longer a school psychologist for the school division" (P22, 1158-1161). Furthermore, schools were not always able to hire the most qualified person.

The staff aren't really qualified technically to deal with this kind of stuff, the, they're just people off the street, like you know what I mean, just go in there or whatever and, and so I mean that's my biggest thing is that they're not going to get the quality of education as they might get in a city if there, you know there's people, more people that know about autism. (P10, 996-1003)

Rural communities faced difficulties recruiting and retaining professionals. In addition to fewer professionals available, rural communities had new graduates who were eager to learn but unfortunately, did not have the knowledge to adequately address their child's needs. Within the rural community, the ability to become well informed about autism was extremely limited. There were little resources to train or instruct the willing people of these communities. Families believed that some school systems had difficulty with integration and stated that there was "not enough trained professionals to deal with

the integration or to provide the tools” (P1, 3758-3760). Lack of collaboration was another difficulty expressed by participants. Due to the perceived notion that the school system was failing their child, some families removed their child and chose to home school to increase educational learning and provide the best possible learning environment. One mother explained her frustrations “the people that know us have been very supportive. It is the school system that has failed him so bad” (P19, 4033-4035).

Families also had difficulty in finding tutors for the ABA program and extreme difficulty when seeking appropriate respite workers.

Less choice of tutors and less available tutors. (P1, 3682-3683)

The challenge though is is that they don’t have respite workers. You have to find your own...and you know you end up getting someone who’s no more skilled than an average baby-sitter but they’ve go to deal with this child that’s difficult for an adult to deal with. (P15, 3776-3784)

Trying to get like a respite worker whose going to come out this way...it’s very difficult. (P9, 1600-1605)

There just was a problem finding tutors and there still is a problem. Like I said with ‘K’, as of December he had been in the program for twenty-five months and only had a tutor for eleven months...and we’re still looking. (P1, 1841-1848)

There’s no one in ‘*name of community*’ who does respite. In the whole ten years of our existence there has been no one. (P13, 1441-1443)

Families did everything to provide the best for their child and although they were content, they still felt that there was more available. This includes more services that were restricted due to the small community that they lived in and more resources that would increase the quality of life in their child’s world. Families became quite frustrated when they heard about what was available within larger surrounding cities but was unavailable to them due to cost, transportation and time. Overall, parents expressed that although there was less of everything, they made the best of what they had.

*Safety and Familiarity*

Although participants experienced less of everything, there were many positive attributes to living in a rural setting that kept parents within their community. Families believed that the rural setting had been a positive experience and a safe place to raise and parent their child. Families felt that they experienced shorter wait times for offered services, smaller class sizes and the familiarity of knowing most people within their community. Families explained how the class sizes were beneficial to their child and the ability to have the same children throughout the child's school years provided familiarity to a child who yearned for repetition and sameness.

Like 'W' will have those twelve people [in his class] until he graduates. (P23, 1613-1614)

Because he was really familiar with the school and the kids, it was the same kids every year, the same twelve boys every single year. (P8, 811-813)

There's 58 kids in the whole school...and uh you know so even when he goes to a new classroom that teacher is not foreign to him...if it was a big school they wouldn't know him at all. They already know all of his little quirks and stuff...so it makes their transition with him easier. (P15, 3365-3380)

Smaller class sizes is, is a big plus. (P1, 2463)

Participants believed the smaller classrooms enabled their child to be more successful.

I'm actually happy that we live in a rural community because I think they'll get more, because the schools smaller and there's not going to be as many people with autism, I think they almost get more attention that way and I like that I kind of know, like you don't know everyone's background, but you kind of know...I just kind of thing it's going to be more beneficial to them being in a small community. (P2, 619-628)

The school system was a wonderful support to rural families given that the teachers, principles, resources teachers and EA's were great to work with. Elementary schools

were often found in the same location of the daycare and preschool, so that the child was able to engage in consistent and familiar locations and peers.

Families liked the safety of the smaller towns and as one participant illustrated “we did live twenty miles north um it helped with the safety, there was no busy streets nearby...if he ran out the front yard it was okay cause there probably isn’t a car coming” (P14, 2654-2663). Others enjoyed the quieter streets and shared that “it’s quiet um there’s no racing cars going down the street” (P22, 2569-2570) while some enjoyed the smaller populations. Families were able to have large yards in which their child would play. As highlighted by one mother “the benefits to this you see my yard, you know we’ve got all the space, the kids have all their, you know they have a trampoline and they have, they have cows, ‘J’ has his own pet calf” (P1, 2434-2437). Parents felt safe to have their child play outside and stated that “here I don’t panic if he’s you know playing in the backyard by himself or with the dog” (P11, 1316-1317). They enjoyed the proximity of the stores, community centres and shopping areas. One parent expressed “it’s so much closer to go do everything, you know walk to the skating rink and skate or you know go to the rec centre and skate” (P11, 1331-1333). Going to rural appointments or getting groceries required less time and took less planning.

Parents took comfort and felt a sense of security in knowing that everybody knew their child and that they had been diagnosed with autism.

He goes in by himself and all the library people know him and they care about him and the people in the grocery store know him and now that they know a little bit more like with the media and that um they’re understanding a little more of what has happened to us too. (P18, 3967-3976)

Whereas where I live, I know my whole street. Everybody on this street know ‘O’s’ autistic. They all know what he looks like. And they all know that if you see him wondering down the road by himself you pick him up and bring him

home...whereas in the city, your neighbour down the street doesn't know. (P6, 3103-3116)

Parents were reassured in knowing that if their child escaped or ran out of the house, someone would look out for them.

If he is missing from our yard, if someone sees him uptown by himself which has not happened, he's run away to the school but he hasn't run away anywhere else...there are enough people that would know...that gives me peace of mind because if I were in an urban setting and he walked off the yard would anyone, no, probably not. (P13, 4641-4666)

If something should happen where "D" was um running down the street not dressed appropriately there would be like a dozen people there to help him. (P14, 2643-2646)

I think living in a smaller community is more forgiving and more tolerable so I think that it's also safer to some degree because as I said I have kids who look out for 'C'. (P17, 3503-3510)

Additionally, being able to see a Sunday school teacher at the post office or the daycare staff at the grocery store was comforting and a positive experience to a child with autism who thrives on repetition and sameness. Familiarity and repetition were vital to the success of a child with autism and being able to recognize teachers within the community brought comfort to participating parents.

It's a small town, it's nice when you go to the grocery store or to Wal-Mart or something and you, you know 'K' will all of a sudden, hi 'J' or hi 'J' you know he, it's like wow look at that...but if you went, if you're in the city we would have never seen these people cause you're just a number. (P11, 1290-1308)

Because we live in a small town, it's the same thing for any little kid that goes to school, like when you live in '*urban centre*' you would never, probably ever see your teacher on the street or anything...he sees his daycare workers on the street, he sees his Sunday School teacher in another place. (P24, 4013-4021)

Although within the rural communities parents experience less of everything with respect to services and programs, they nonetheless, experienced more with respect to living in an environment that was safe, familiar, and supportive.



### *A Family of Support*

Parents found that over time and through awareness the rural community became a family of support to their family and their child with autism. Although there were difficulties with stigmatism, through teaching and awareness, communities collectively helped enable the family to best support their child. One parent shared the support given by her community “inclusion was huge in our community...and ‘N’ has been one hundred percent included in everything” (P14, 2398-2421). Friends, family members, neighbours and community members sought out participating families to share all that they knew, heard or learned about autism. Communities openly welcomed the diagnosis of autism and looked out for their child and for their safety. The support system shown and given by each of the small communities acted as a comfort that surrounded each of these families. Although people did not understand what it was like to parent a child with autism, they shared whatever knowledge they may have had.

But that’s the benefit is you do have such a support network that are constantly looking out for the best interest of your son. (P6, 3799-3801)

It’s actually quite amazing how many people have phoned me up and, and just kind of said, such and such a channel on the TV in five minutes they’re having something about you know we’ve got several calls like that...and I’ve been surprised how much information there actually is uh coming out about autism. (P24, 1571-1582)

That’s the other thing yeah about being rural is that there’s somebody always going to try to find your somebody...they’re always; people are always going to be out there saying she is looking for somebody who can do this. (P6, 5342-5350)

Families found rural communities to be more forgiving. One parent expressed that “being in a smaller community is more forgiving. And more tolerable so I think that it’s also safer to some degree because as I said I have kids how look out for ‘C’” (P17, 3503-3510). Other parents have found rural communities to have more understanding.

I think there's more understanding. I think, I'm actually happy that we live in a rural community because I think they'll get more, because the schools smaller and there's not going to be as many people with autism, I think they almost get more attention that way. (P2, 618-623)

Even though there were some drawbacks to living rurally, families embraced the positives due to the social supports and school systems; "positively because of the social supports we've had and the school. The school has been phenomenal. He is treated one-on-one with all his class, all the kids know" (P15, 3353-3359). Besides a few, majority of the families had excellent things to say about the rural school divisions.

We're really lucky at the school to have excellent teachers and really good support, really good TA's. (P8, 747-749)

Even though the school division doesn't have the expertise, the fact that you know all the teachers, you know that there will be communication, you know that they're open to accepting your child. (P1, 2455-2459)

Families believed that although services may not be as high quality or more experienced, the support families received outweighed any downfalls. As one parent described "we might not get the same high quality but we'll get more, I don't know, personal or compassionate care...you know in the sense that people will know each other more on a personal level as oppose to a number" (P17, 3601-3609). Child development workers, resource workers, teachers and TA's often went out of their way to help create the best environment for the child to be successful.

That year his kindergarten teacher offered to go with me...so we went together...so actually that was good cause without her there I probably wouldn't have actually gone to any of the courses, I would have just skipped out. (P8, 628-639)

The child development worker she went to a conference about autism and she had to go to Winnipeg for that. (P26, 2570-2572)

As a result, families found that they were "surrounded by a community that knows you...and everybody knows both my boys" (P14, 2634-2639) and "in terms of community

and people, you, you can benefit because people will know you better...if you're in the city and you live on a city block, you may know your neighbour next door to you; you don't know your entire street" (P6, 3088-3099). Parents credited their community in their ability to survive life with autism and believed that it would be difficult to live in a bigger city. By becoming open and visible with autism, families were able to draw out a large network of support and compassion that according to parents in this study, was not found in large urban settings.

### *A Renewed Sense of Parenting*

Despite the challenges that parents faced parenting a child with autism, they nonetheless reinforced that it was their child with autism that gave them the strength and hope to continue on. Each milestone, goal or unexpected action experienced by the child, brought much joy in the parents' lives. Persistence and dedication paid off for many families and this was seen through their beaming smiles and encouraging words. Participating families were able to give hope to those faced with an autism diagnosis that only saw a dark future. Parents expressed that "if I could find a way to show parents in a snapshot this is what you were told today, but this is where they're going to be in ten years don't give up the hope because if you give up so will everybody else" (P22, 3674-3677). Parents were proud of each and every accomplishment and how far their child had come. To gain a renewed sense of parenting, three strategies were expressed by parents (a) cherishing the little things, (b) the importance of humour and patience, and (c) acceptance and preparation for the future.

*Cherish the Little Things*

It was the child that enabled parents to get through each day, provided them strength and gave them hope for a bright future. It was the little things that made each day worthwhile and the expected, unexpected that brought joy in lives of participating families. Although there were days when parents could not get out of bed and days filled with chaos, there was that moment; that moment when their child said his first word at age three, when they used a straw for the first time, when they looked them in the eye or even if they just sat in one place for just twenty seconds. It was those moments that everything went calm and when this happened, parents were able to take a breath and then continued on with all the chaos, with all the battles and with all the days that they did not want to get out of bed. Families shared that it was the little things that most people take for granted that meant so much to them.

Every little thing that so many parents take for granted is kind of a big thing to me...like 'E' being able to talk and just different things that he started saying was huge for me. Because I didn't know if he would ever be able to talk. (P2, 536-547)

When you have an autistic child everything they do is like a celebration. (P6, 4532-4533)

You start to just not take anything for granted...every little time that he would give you eye contact we made a big deal about it...If he would go over and try to hug one of his siblings we were celebrating. (P4, 2250-2260)

Any kind of a goal he reached was glorious. (P11, 734-735)

Parents shared that each milestone reached was a time of happiness and joy and brought hope to their family.

I mean every day the child amazes me. (P23, 4072-4073)

But every little thing that you never expected them to do, because when they're diagnosed you're given such a low idea of what your child is going to accomplish.

I don't know if they're, they don't want to set your hopes up so high for disappointment...start you down low and then everything's wonderful. (P6, 4568-4577)

Each parent shared multiple stories of their child's little accomplishments and even how the simple achievements such as making eye contact and a connection were so important.

You know when he got toilet trained and we all crammed into that small bathroom. We were high fiving and we were you know those are things that I remember...with him...you took it and you just wanted to hang on because you just through you know we worked so hard for that. (P4, 2264-2279)

And you know after not speaking for so long and then hearing that little voice again, it was really exciting. (P7, 962-964)

I mean it's just small things like that that you know putting together two and three word sentences...sitting down at the table and playing while I was making supper. (P11, 793-800)

When he started to drink from a straw we had a big party...and our friends like that were there for supper that night wondered what the hell was going on, and I'm like he learned to drink from a straw...we don't have to carry a sippy cup anymore, it's like fantastic. (P23, 434-446)

Affection and closeness were never taken for granted and type of bonding brought great joy to families and parents.

She's very affectionate she's always coming and wants hugs...and always holding my hand and always smiling and happy looking. She's not this emotionless zombie baby that she seemed to be. (P26, 315-322)

He will still come up and just give you a hug out of the blue...for no reason at all type of thing. (P17, 3822-3828)

He's very affectionate. And loving and deep sometimes of what he says. (P15, 2012-2016)

When given a diagnosis of autism, parents were led to believe that their child would not be affectionate and instead be locked in their own world. Parents cherished each moment of affection and this enabled a connection that they never imagined.

Probably last year at age eleven um she, she said to me and my husband, I love you, and she said, she looked and she said, I, I'll always love you and then she said to 'B' I'll always love you and then she said, I'll always love you guys. (P3, 752-756)

Parents also experienced the joy of having their child fit in with their peers.

All the kids made this semi-circle around they're like go 'W', go 'W' I'm like oh and I walk out and I'm bawling my eyes out. I'm like oh my God he's fitting in I can't believe it. (P22, 2115-2119)

And I sit there and it warms my heart because he's referencing all his little peers in his class to see what he needs to do. He has little friends, like he likes to go to school. (P23, 4117-4120)

Parents learned to cherish these moments, enjoyed every accomplishment and bonded together as a family.

I've always said there must be something in their day that is good and I don't care whether you know it was very small to you, you have to write it in their communication book because parents need to hear the good stuff instead of what they can't do and what they didn't do and how they acted out. (P22, 1231-1236)

You know like every, you get so much more excitement out of every little thing that they accomplish. (P6, 4557-4559)

We've had huge milestones in that we can go to movies together as a family, we can go mini-golfing, we can go to restaurants, we're talking about taking a trip so those are, there's always things you think about to make sure that it runs smoothly. (P13, 4361-4365)

Overall, parents believed that "every day is a joy" (P1, 2195) and to cherish each moment no matter how small because their child was amazing and loveable. One parent shared "it's almost like he's like this little sponge that now that it's starting to go he's just soaking it all in" (P4, 1988-1989). Parents lived for these moments and cherished them greatly. Parents stressed the importance of enjoying "the little things and don't always fight against, he doesn't have to be the same as everybody else... He has to be the best that he can be" (P13, 5043-5049). These were the moments that enabled parents renewed

strength and the ability to continue to make autism visible and strive for the best their child could be.

*The Importance of Humour and Patience*

Parents spoke about the ability to laugh and have patience as two extremely important qualities key to the success of parenting a child with autism. One mother described “he made us laugh a lot and he make us, and he taught us lots of patience...so that um I think we know how to deal with human beings in general on a better level” (P14, 1511-1517). Being able to laugh and have fun made the dark days lighter as shared by one parent “‘T’ is more severe, quite a bit more severe and yet he had this sense of humour about him that is just absolutely hilarious” (P22, 2158-2164). Laughter was often used as a coping mechanism, as a way to deal with the day to day life of autism and to enable families to remain positive, even if it was only for a moment. Seeing their child laugh enabled parents to connect with their child.

He’s got this infectious laugh that just makes everybody laugh and he’s a beautiful kid. (P9, 1960-1961)

You know if he spoke I’m sure he’d, he’d be the joker in the family you know and stuff. But he doesn’t actually speak so just by his actions he’s uh, and he knows he’s funny, you know he’ll laugh...so you know little things like that, um are, are great because it wasn’t that long ago when he just was not you know not like that at all. (P5, 1632-1641)

Connection through laughter was important to these families. One mother shared that “when he was little well you know when we were together and you know I’d pin him on the bed and tickle the hell out of him and he would just laugh gleefully” (P21, 3712-3715). Moreover, parents learn to laugh at their child’s unique characteristics.

Teasing, lots of teasing, cause he just, you know what I mean not even looking at you, he’s looking past you, hi mommy, supper, and you know he wants to know

what's for supper and it's like, an you just roll your eyes and you're like, he's never going to change. (P14, 3751-3756)

Conversation with him is never dull. (P17, 3791)

Along with learning to laugh, parents learned patience and flexibility. Learning patience was essential to the survival of parenting a child with autism.

I have always been a patient person but I think I've been even more so just because you have to be and there's no use driving myself crazy trying to do I don't know it, I might as well stay calm cause it's not going to help just to lose it on them anyways cause they just don't, they'll just tune you out so. (P10, 1369-1374)

Parents showed persistent patience for the child and their child's abilities. Parents showed incredible strength and their patience was seen as a virtue. Overall, laughter and patience were vital to maintaining balance and surviving in the busy world of autism.

#### *Acceptance and Preparation for the Future*

When faced with the diagnosis of autism, parents left the doctor's office with a grim and dark future. It was not until parents began to experience life with autism and began to do their own research, that they were able to see the light in their journey.

I started finding out that there are more, is more help for autism, so that it's not just a hopeless thing, your kids not just going to stay at that same level that they were when they were diagnosed. I started realizing that there is hope for them if not completely come out of it, to get them to a point where they can function. Like my goal is for them ultimately to be able to live a life where they don't need me all the time. I want them to be able to live on their own and have their own place and stuff like that, and I thought if they were diagnosed with that, that would never happen. But I also realize it's a huge spectrum. (P2, 480-491)

Obtaining a diagnosis for what their child had enabled parents a sense of relief when it came to describing the unique characteristics displayed by their child. A diagnosis allowed parents to acknowledge that something was different with their child and that the



onus did not fall upon them and their parenting skills. Parents were able take a step back instead of attempting to push forward with no avail.

Before you're always trying to push them to do these things that they obviously weren't going to do but you thought they should be doing it and not it's kind of like okay maybe they, I mean they might eventually but it's going to take time so you just kind of relax a little more and try and let them do it. (P10, 687-693)

While searching for knowledge about autism parents were able to increase their understanding of their child and therefore, learned to help them succeed.

Learning more about autism as a, as a state of existence has really taken a lot of the stress of being a parent to a kid with autism because now I know why he's that way, instead of wishing that was different and not understanding why...and honestly he's such a great kid, I'm okay, you know I don't wish he was any other way. (P8, 713-722)

Parents embraced autism and acknowledged that their child had potential. Although there were many unknowns about autism, parent still supported their child in the best possible environment they could make.

We've tried to fulfill his dreams but we want him to, to live up to expectations of just being a typical, and I don't mean extraordinary, I don't mean, I don't mean typical even as far as like you or I. You know I mean typical for him. (P14, 3683-3690)

Parents never stopped believing in their child, acknowledged that growth and development may take time and stated that "we still have the same dreams but you know it may take us longer to get there" (P22, 1526-1527). They believed that their child could be "the best that he can be" (P13, 5049). Parents learned from their child and began to see the world different than they would have ever imagined.

I love having kids that are a bit different too cause its, its, they've just got such a different perspective of the world which is kind of fun. (P2, 1206-1208)

We learn more from him than he will ever learn in his lifetime...people like that I think touch, touch communities far more than ever before probably because of exposure. (P13, 5053-5061)

I think we know how to deal with human beings in general on a better level. (P14, 1516-1517)

They look at things totally differently. You know sometimes he just reaches into a social situation and pulls out like this absolute truth...everybody else would be not even thinking of that or noticing that. And he will draw your attention to it. (P9, 1762-1770)

Parents had mixed feelings about the future. Most parents described a day to day approach and “stopped looking about ten years in the future...I don’t look in the future anymore, I just look at what’s going on right now and what we’re doing for them now” (P2, 501-512), while others always had concerns about the future. Some parents looked ahead and began to put money aside, and as shared by one participant “we have the RDSP for ‘W’, I mean we’re putting money away for ‘W’ to go to school” (P23, 4177-4179). Parents worried about what will occur when their child grew older. They worried about what would happen when they passed away and who would take care of their child. Parents worried whether their child would fit into society and whether their child will grow up and gain independence. Parents tried to control as much as possible, as best of possible.

As a result, parents believed that “eventually you have to accept the fact that your child is autistic and not be embarrassed or afraid of them” (P17, 4437-4439). Parents learned to accept their child for who they were and yet still wanted them to be the best they could be.

Once you accept that this is the person that he is and there’s no, no one hiding in there waiting to get out that this is ‘S’ and this is him in all of his glory, we stand to learn a lot...just enjoy the little things and don’t fight against, he doesn’t have to be the same as everybody else. (P13, 5036-5045)

Families did not look at autism as a disability but rather saw it as an ability. They believed in their child and all that they could be. Parents believed that dwelling on the fact that your child had autism did not improve the situation or enable the best environment.

You know it does no good to beat your chest and say oh autism is so awful, you know my poor son's got it, I'm like you know there's people with kids that are normal that are also worried because they don't have any friends...or they're not doing good in school, like this is what parenting look like you know, this is it, it doesn't get easier. (P8, 1350-1365)

Overall, parents embraced their child with all their strengths and weaknesses, planned for the known and prepared for the unknown.

#### Chapter Summary

Chapter five presented the demographic data that were collected to provide a picture of the participating families. The essence of the parents' experience and supporting themes were described. Making the invisible, visible emerged as the essence or overarching theme representing the lived experience of parenting a child with autism. Parents began their journey with autism at an early age. After initial diagnosis, they learned what autism meant to them and their family. From this they began to educate society and their surrounding community by constantly advocating on their child's behalf. Parents did things on their own, and although they felt isolated in terms of services and professional support, they felt embraced by their community who loved and accepted them and their child for who they were and what they could be. Once autism became visible within their community, the community acted as a support system for families and enabled families to see the many positives to parenting a child with autism while living in a rural area. Following this chapter, chapter six presents the discussion, an

overview of the conceptual framework, methodological limitations and strengths and recommendations for practice and research.

## Chapter VI: Discussion of Findings

### Introduction

This chapter presents a discussion of the findings. The purpose of this phenomenology inquiry was to explore the lived experience and arrive at an understanding of the meanings rural parents assigned to parenting a child with autism. The essence of this experience, as well as the themes supporting this essence, and the recommendations for health care professionals were revealed through analysis of the descriptions. In this chapter, these findings are discussed and compared to those in the literature.

This discussion incorporated a comparison of previous research findings to those of this study. Specifically included are those findings that described parenting a child with disabilities, including those with autism. Moreover, although the experience of parenting a child with autism in a rural setting was unknown, comparison between this study and research on parents parenting a child with disabilities while living rurally were also considered. Recommendations by parents for professionals and a discussion about the Life Needs Model are also reviewed. Furthermore, limitations and strengths to this research study were discussed, and recommendations for practice and research were provided.

### The Essence of the Experience

Making the invisible, visible emerged as the ultimate essence of parents' lived experience of parenting a child with autism while living in a rural area. Through their constant battles and endless advocating, parents had to make the invisible condition of autism; visible to themselves, their family, and most importantly their community. Once

visible, families found that they were embraced by their community and the stigmatism that was first seen was gone. In turn, parents were able to provide the best possible life for their child in an environment that enabled learning.

The invisibility of autism is documented in the literature (Cashin, 2004; Glass, 2001, Gray, 1993; 2002; Woodgate et al., 2008). Comparable to the research of Woodgate et al. and Gray, parents in this study described similar feelings of isolation when autism was invisible in their community. Fortunately, for parents in this study, this isolation felt from others dissipated once autism became visible in their community. Unlike Woodgate et al.'s study, parents failed to use the term isolation to define life with autism, rather to only use the word to describe the lack of available professional support and services. The support rural communities gave provided parents with sense of inclusion and therefore, disbanded the sense of isolation that was described by the parents of Woodgate et al.'s and McKay and Goddard's (2006) research. In making the invisible, visible, parents in this study had to overcome three barriers: (a) he's not the rainman (b) society's lack of knowledge and understanding, and (c) doing it on our own. To make autism visible, parents themselves had to learn everything they could about autism and share this information with those that surrounded them.

At the time of diagnosis, most parents were extremely limited in their knowledge about autism with most parents making reference to the movie Rain Man (1988) starring Dustin Hoffman and Tom Cruise. He's not the Rain Man was a recurring reaction of parents in this study. Limited knowledge and understanding of autism led to initial reactions of fear, denial, and shock. Sen and Yurtsever (2007) explored the initial reactions of parents when they first learned that their child was disabled. Just like the

parents of children with autism, shock, denial and suffering and depression were described as primary reactions of parents in the study by Sen and Yurtsever. Guilt, indecision, anger and shame were reported as secondary reactions of parents while tertiary reactions included bargaining, acceptance, and adaptation. Sen and Yurtsever found that to reach acceptance, families had to get to know their disabled child and understand their child and their child's disability. In this study of rural families, autism became visible to parents by the research and education sought out by parents. In understanding autism, parents became empowered to make the right choices for their child, and this allowed them to provide their child and increased their quality of life. Understanding autism enabled parents to understand their child.

Lack of knowledge and understanding from society was cause for concern for participating families. Because one cannot see autism on the outside, the child was expected to behave a certain way. Difficulties, frustrations, and stigmatism arose when the child with autism acted out of the expectation. The literature described the difficulties that parents experience related to the invisibility of autism. Difficulties included embarrassment in social settings, hostile or insensitive reactions from the public when the child behaved inappropriately, and feelings of being judged by other parents based on their child actions (Cashin, 2004; Glass, 2001; Gray 1993, 2002). Due to the child's normal physical appearance, autism appears invisible to the public and therefore, any undesired behaviour may be viewed to be a reflection of bad parenting rather than that of the disability. Gray (1993, 2002) explained how the normal appearance by a child with autism, combined with the lack of knowledge from society increased the incidents of hostile remarks to parents in regards to any unwanted and inappropriate behaviour from

their child. In Gray's studies (1993, 2002), the invisibility of autism was associated with increased stress in families. Exacerbating this stress was the extreme disruptive behaviour and social inappropriateness of the child with autism (Gray 1993, 2002). The difference found in the literature and that of this study, was that once autism became visible within the community, parents reported a decrease in stigmatism. Instead of feeling isolated and alone, families were embraced by a community that loved and supported them. Nevertheless, Gray (2002) concluded that increasing the public awareness of autism may reduce the stigma attached to parenting a child with autism.

From diagnosis to treatment to present time, doing it on our own emerged as a major theme to the essence of making the invisible, visible. Parents described their frustrations with the lack of appropriate follow up care following the diagnosis of autism. Parents received a diagnosis and were sent back to their rural community with little knowledge regarding the characteristics and demands of autism. Researching autism and accessing services became the responsibility of parents. Parents learned the needs of their child and how to fight for the services and resources that their child deserved. They increased their knowledge about autism, and parents became aware of what their community had to offer.

Woodgate et al.'s (2008) discovered that parents parenting a child with autism had similar feelings to the parents in this study and described the essence of their study as "living in a world of our own." Parents in Woodgate et al.'s study believed that they were on their own for all aspects of daily living, especially those related to the difficulties and challenges of parenting a child with autism. Furthermore, Mackey and Goddard (2006) also found that mothers' parenting a child with intellectual disabilities described feelings



of being on their own. In addition to being on their own, as reported by Woodgate et al. and Mackey and Goddard, families in this rural study were often the one and only in their community that had a child diagnosed with autism. Participating parents faced multiple challenges and barriers due to living in a rural area and having few resources. Getting the required support for their child with autism only came through persistence and determination. Parents learned to advocate and battled the health care, social and educational systems to help their child reach their full potential.

### Themes

Five supporting themes validated the essence of making the invisible, visible and are thoroughly discussed in this section. The supporting themes include: (1) using autism to enable, (2) lifelong advocating, (3) centering autism within the family, (4) the ups and downs of living rurally, and (5) a renewed sense of parenting.

#### *Using Autism to Enable*

Although a diagnosis was unsettling to parents, parents reinforced that they had nothing without this diagnosis. Despite the fact that there is no known cure for autism, it is believed that early implementation of specific strategies and programs individualized to the developmental needs of the child and their family is beneficial for improved prognosis (Committee on Children with Disabilities, 2001). Obtaining a diagnosis was the first step for parents in this study. Unfortunately, this step only occurred after a delayed waiting period due to the combined difficulties of obtaining a diagnosis while living in a rural area. Although characteristics of autism were often displayed in the early years, the research reports similar delays in diagnosis and has shown that diagnosis often does not occur until late childhood (Howlin & Asgharian, 1999; Howlin & Moore, 1997).

Specific to this rural study, parents spoke of difficulties of receiving a referral from rural physicians because of invisibility of the disability, and the false reassurance from physician's that their child was just delayed in their development. For parents in this study, a delay in diagnosis caused frustration, especially for those who knew something was wrong but could not access the services due to a lack of formal diagnosis. To ensure optimal time for early intervention, diagnosing a child with autism by age two should be the goal of all health care providers, including rural physicians (Caronna et al., 2008; Moore & Godson, 2003). In the literature, Gray (1993) reported the challenges and difficulties that parents faced when attempting to obtain an accurate diagnosis of autism in an appropriate time frame. In addition, Lin, Tsai and Chang (2008) found that as a coping mechanism parents made every effort to ensure that their child received a timely diagnosis of autism to obtain the early recommended treatment.

Parents expressed that to use autism to enable, they had to learn how to: (a) play the autism card, and (b) deal with barriers. When playing the autism card, parents were able to obtain the required services for their child. Parents maintained that receiving a diagnosis was not seen as something negative, but rather to facilitate success in their child. As Dymond, Gilson and Myran (2007) described, without a diagnosis parents could not obtain the appropriate services for their child. A diagnosis of autism gave parents in Dymond et al.'s study and this study a card to play to achieve the required resources needed by their child. With a diagnosis, parents in this study were able to access services such as speech, occupational, and physical therapy. Moreover, parents could now apply for funding to provide the supports needed to help their child develop to

their full potential. Playing the autism card was similar to what Sperry, Whaley, Shaw and Brame (1999) described as becoming the “squeaky wheel.”

Multiple barriers existed for parents in this rural study. According to the literature, parents in Dymond et al.’s (2007) study felt that they were forced to “jump through hoops” to obtain the required services for their child with autism. Similar to the parents in Dymond et al.’s study, parents in this study were passionate about receiving the best possible care for their child but unfortunately, faced many barriers along the way. Parents experienced frustration as services that were meant to enable children with autism advance their development, remained inaccessible. Woodgate et al. (2008) found that parents of children with autism experienced an unsupportive and inaccessible “system.” Parents defined the system as all of the appropriate services including health care professions and the educational setting that were put in place to help children with autism become successful. Furthermore, Lutenbacher et al. (2005) and Ray (2002) found that parents parenting a child with a disability or chronic illness identified multiple challenges in the health, social services and educational systems as well. “Working the systems” was described by Ray as the frustrations that parents in her study had with working with the health, social services and educational systems. Unfortunately, as described by this current study, living in a rural setting only increased the risk for system related problems due to distance from an urban centre and lack of accessibility. Parents in this rural study defined the system in the same way that the parents in Woodgate et al. and Ray’s studies did and all parents believed that their child had a right to receive quality education with the required support. As Woodgate et al. discovered parents learned every dimension of

autism to navigate and ensure the effective functioning of the system and to overcome the encountered barriers.

Parents in rural communities described the difficulties of obtaining services due to inaccessibility and unavailability, thereby requiring them to drive to larger neighbouring communities or urban cities. According to parents, rural communities had less choice and fewer available options. Although research in the rural setting is limited, there is some literature describing the difficulty in accessing services for both adults and children with disabilities (Arcury et al., 2005; Buchanan et al., 2006; Dymond et al., 2007; O’Callaghan et al., 2005; Scott-Findlay & Chalmers, 2001; Skinner & Slifkin, 2007). O’Callaghan, et al. found that in their study of rural parents of children who required speech therapy, parents experienced access barriers due to lack of availability and limited choice of available speech therapists and therefore, faced long wait lists or were forced to drive to larger centres. In addition to the access barriers documented by O’Callaghan et al., parents in this study described further barriers to accessing services that were related to unfilled positions due to maternity leaves or leave of absences.

Further barriers faced by participating parents included: the difficulties when having to travel to a larger city, and the preparation needed to obtain and access the available services. The increased preparation when parenting a child with disabilities is documented in the literature (Hewitt-Taylor, 2005; Lutenbacher et al., 2005; MacDonald & Callery, 2007; Yantzi et al., 2006). Both Ray (2002) and Vickers and Parris (2005) discussed making the invisible, visible in the context of caring for children with disabilities. However, instead of having a focus on the disability itself, these authors describe parents’ experiences of making visible, the invisible responsibilities and

challenges that incur when caring for a child with disabilities. The described day to day activities were extremely time-consuming, involved great intensity and duration, and required a lifelong commitment, but remained invisible (Ray). Comparable to the studies by Ray and Vickers and Parris, parents in this study spoke to the time and commitment spent preparing their child to function in the social world and in their community. Parents described the consuming daily activities such as grooming, dressing, and communication that all took longer with a child with autism. Although they did not have to learn specific medical aspects as the parents in Ray's study, they in turn had to be vigilant, consistent, and prepared for the unknowns of autism.

Overall, parents learned to play the autism card and overcome the barriers in the health, social services, and educational systems. Parents became insistent that conditions were in place to create the most optimal environment that allowed the greatest success in their child.

### *Lifelong Advocating*

Becoming an advocator while parenting a child with disabilities, including those with autism, is well documented in the literature (Aman, 2005; Lauver, 2008; Lutenbacher et al., 2005; Murphy et al., 2006; Ryan & Runswick-Cole, 2008; Woodgate et al., 2008). Lutenbacher et al. found that parents of children with special health care needs became experts in their child's condition and constantly advocated on their behalf. Continuously advocating for a child with a disability was seen as a major source of stress in Murphy et al.'s study. Constantly advocating was also the experience for parents in this study. Parents were self-motivators and were always looking out for the best interests of their child. Parents continuously learned how to parent the ever-changing needs of

their child, and to provide them with the best care possible. Parents believed that learning to advocate for children with disabilities was one of the most important lessons to learn in life.

For this study, parents employed two strategies to advocate for their child: (a) setting up an environment for success, and (b) picking and choosing your battles. For families in this study, preparing an environment for success meant that parents continuously advocated for their child and did all that they could to achieve the greatest success in their child. From visual schedules to social stories and structure, families created an environment that aided in routine and avoided meltdowns. Creating an appropriate school environment was described by Dymond et al. (2007) as parents advocated for an appropriate educational program to meet the individual needs of their child with disabilities. Parents strived to obtain the best educational environment to ensure success in their child. Similar the experiences of Dymond et al. and Lutenbacher et al. (2005) studies, even the parents in this study with positive experiences with the school, addressed the immense amount of time, energy, and preparation that were required to adequately meet their child's needs. Meeting their child's needs occurred through trial and error, and persistence and determination. Moreover, many parents rearranged their homes to initiate learning. Parents turned bedrooms into classrooms and basements into playrooms.

Planning and preparation occurred every day. Parents had to teach and spend many one on one hours preparing their child for upcoming events or new situations. Ray (2002) described this planning and preparation as invisible work that was extremely time consuming and often went unnoticed. Similar to parents in Dymond et al. (2007) and

Ray's studies, parents in this study shared multiple stories of the preparation that takes place for their child to be successful. Ray described this work as "parenting plus" in her study of parents of children with disabilities and Woodgate et al. (2008) referred to this as "vigilant parenting." For parents in this study, they believed that failure only resulted from a lack of preparation rather than failure due to autism.

As advocates, parents learned to pick and choose the battles. They did their research and did not take the laid back approach to autism. Ultimately, it was those battles that meant the most that kept parents pushing, insisting and fighting. Access problems were cause for parents in this study to have to fight for the needs of their children. They became relentless in the pursuit of accessing equal services and obtaining support. They often had to convince others that it was the best interests of the child and not the system that should be the concern. This fight for services and equality shown by parents of children with disabilities is reported in the literature. Woodgate et al. (2008) described parents' fight to make the system work for them and their child. While Dymond et al. (2007) and Scorgie and Sobsey (2000) revealed the exhaustion parents experienced because of the fight to obtain services.

In the end, parents were left with no choice but to advocate for their child due to the invisibility of the disability. Through an array of approaches, parents advocated on their child's behalf, learned to create an appropriate environment and fight for the things that mattered. Although much of this work was invisible as described by Ray (2002), parents in fact made it visible through their constant battles to ensure that their child received the best quality of life.

*Centering Autism within the Family*

To the parents in this study, the diagnosis of autism became the focus of their family and their life. Parents described how life slowly began to revolve around the child with autism. Autism became the centre of the family and parenting now included: (a) multiple roles, (b) a focus on their child's needs, (c) finding a balance, and (d) doing everything we can. Parents fulfilled multiple roles while leaving their own needs behind. Similar to Sen and Yurtsever's (2007) study, parents in this study experienced added responsibilities such as teacher, advocator, and expert in their child's disability. Parents taught themselves and their child ABA therapy. Many parents assumed responsibility for speech, occupational, and physical therapy. Some parents even learned how to play musical instruments so that they could teach and connect with their child, while the majority of parents learned to cut their child's hair. Parents became coaches of sports teams and sought opportunities to involve their child in social situations. Parents searched for activities for their child to participate and were always looking ways to have their child interact with others. Parents in this study were the spearhead of community activities, and created environments for their child to have fun and be challenged. Ray (2002) found similar results in her study of parents of children with disabilities in that parents did whatever they could to help their child acquire skills and achieve delayed abilities. "Acquired roles" was how Scorgie and Sobsey (2000) described the multiple new responsibilities that parents attained when parenting a child with disabilities. Here, the authors noted that despite the difficulties, parents viewed these acquired roles as enrichment to their lives. Although parents in this study did not describe the life enrichment as expressed by those in Scorgie and Sobsey's study, parents in this rural



study felt enriched and rewarded by the positive changes and appropriate social interaction that they enabled in their child.

The work force was another area of concern for parents in this study. Many had to rearrange their work schedules or change or quit their job due to the high demands of parenting a child with autism. Both Sen and Yurtsever (2007) and Thyen et al. (1999) found that multiple parents caring for a child with disabilities had to quit or change their job to meet the needs and demands of their child. Unfortunately, quitting or changing a job was a difficult decision in a time of increasing costs due to caring for their child with disabilities.

Multiple studies document the nature of parents of children with disabilities to focus on their child's health and needs while putting their own needs aside (Brandon, 2007; DeGrace 2004; MacDonald & Callery, 2007; McKay & Goddard, 2006; Murphy et al., 2006; Scorgie & Sobsey, 2000; Vickers & Parris, 2005). Due to the increased demands of caring for a child with disabilities, parents became constant caretakers of their child's activities including feeding, dressing, and bathing. A qualitative study done by DeGrace observed that parents of children with autism lived their life around the needs and desires of their child. Parents lived moment to moment and relied on routines to meet the demands of daily life with autism. Similar to the parents in DeGrace's study, parents in this study experienced similar situations as each parent described putting their child's needs ahead of their own and doing everything they could to provide the best life for their child. Additionally, Mackey and Goddard found that due to the increased work involved in taking care of a child with intellectual disabilities, there was a significant focus on the child's health rather than that of the parents' own health.

A slight difference found between the mothers of Mackey and Goddard's (2006) study and those of this study, was that although the needs of parents were often put aside, parents of this study did realize the importance of addressing their own needs as significant to their own survival, and a way of finding balance in the chaotic life of autism. Vickers and Parris (2005) echoed this finding when they found that although the mothers in their study were self-sacrificing, the mothers did not believe that their needs should come last nor did they feel that this was an acceptable practice. Scorgie and Sobsey (2000) found that parents were constantly striving to make time for their own personal needs amidst the demands of caring for a child with disabilities. Cashin (2004) found that parents of children with autism experienced less of everything due to the high demands of caring for a child with autism. The parents' loss of self as described by Cashin was not experienced by parents in this study as they acknowledged that they had to take time for themselves and strive for balance. Striving for and finding balance was also an important finding in Woodgate et al.'s (2008) study where the authors found that parents believed it was important to create a healthy balance between parenting a child with autism and other aspects of life to sustain the self and family. Over time parents learned to seek balance by taking breaks and obtaining all available support.

For participants that were married, balance between each other was also significant. Although some parents faced difficulties with their marriage, many reported that parenting a child with autism in fact brought them closer together and enabled balance. Parents stressed the important of maintaining balance within their family, as well as between themselves. Scorgie and Sobsey (2000) found that parents reported a stronger marriage with improvements in communication skills when faced with parenting a child

with disabilities and concluded that a strong spousal relationship was related to healthy family outcomes.

Overall, parents in this study parented without question and did whatever they could, whenever they could, with whatever they had. Parents believed in the “try everything” approach and learned through trial and error. Parents sought out different treatment options, diet changes and biomedical models. Although parents acquired multiple roles and faced many unmet needs, parents strived for balance while parenting a child with autism in a rural area.

### *The Ups and Downs of Living Rurally*

For parents parenting a child with autism, living in a rural area revealed both positive and negative attributes. Three aspects of living rurally demonstrated the ups and downs to parenting a child with autism: (a) less of everything, (b) safety and familiarity, and (c) a family of support.

Parents in this study found that there was less of everything including less professional support, respite, variety and choice of services and less use of technology. Lack of appropriate respite is documented in the literature (Lutenbacher et al., 2005; Lauver, 2008; Ray, 2002; Yantzi et al., 2006). For parents in this study not only was there a lack of available respite workers, parents believed that there was a lack of available trained individuals to provide the needed respite. Although parents were provided with the funding for respite, obtaining an appropriate respite worker was extremely challenging and families were often left with no respite services. This same difficulty was echoed in the parents of this study who had to obtain tutors to work with their child in the ABA treatment program. As reported by Lutenbacher et al., finding respite workers was

especially difficult for parents who had children with complex medical or behavioural-related issues. For the participating families living in rural communities, further limitations were encountered when families faced problems with a professional or a specific service. Parents experienced difficulties with finding the appropriate professional fit between professional and child due to lack of choice. Skinner and Slifkin (2007) found that there was a definite lack of health care professionals within the rural setting and that parents in that study felt that the type of professionals required were not available. Difficulties due to living rurally also occurred when services became unavailable because of unfilled positions. Rural communities faced difficulties with recruiting professionals into their area and this led to gaps in services and disruption to the child's environment. Parents were forced to wait or seek alternative services that included driving long distances and paying for private services that would normally be covered. Although this study reinforced the difficulties to living in a rural area and parenting a child with autism, there is minimal literature on what families experience when a services becomes unavailable and how parents cope with this disadvantage. However, in the study by O'Callaghan et al. (2005) the authors included recommendations such as increased funding to support increasing health care professionals in the rural and remote areas, along with increased incentives to attract health care professionals while Marcin et al. (2004) explored the use of telemedicine as a way of improving services.

Safety, familiarity and support were the overwhelming positive aspects to living in a rural area. To parents in this study, these aspects outweighed the negative qualities of living in a rural community. Parents believed that the rural area was a safe place to raise their family and parent their child with autism. With its quieter streets, smaller

populations and larger yards, the rural community brought comfort to participating parents. Families felt that they experienced shorter wait times of offered services, smaller classroom sizes and the familiarity of knowing most people within their community. Smaller classroom sizes and lower staff-to-student ratios were perceived needs by the parents of children with autism in Dymond et al.'s (2007) study. Parents in this rural study took comfort and felt a sense of security in knowing that people would look out for their child and the familiarity of seeing teachers and daycare workers in the community brought a positive experience to a child with autism who thrived on repetition.

Parents found that the rural community became a family of support to their family and their child with autism. Parallel to the parents in this study, Scott-Findlay and Chalmers (2001) found that the rural parents of children with cancer received extensive support from family, friends, and their community. It was found that when autism or cancer as in Scott-Findlay and Chalmers study, became visible to rural communities, these communities provided support which enabled families to feel loved and strengthen while going through difficult times. Parents believed that rural communities were more forgiving and have greater understanding. Parents expressed their gratitude to the teacher and workers who go out of their way to help create the best environment for their child to be successful.

#### *A Renewed Sense of Parenting*

Despite the challenges that faced parents parenting a child with autism, it was the child that gave them hope and strength to continue on in life. Over time, parents were able to regain a sense of control over the diagnosis of autism and were given a renewed sense of parenting. Parents described their child's positive contributions to life and how

this affected and renewed them. Each unexpected action or achievement of a milestone brought great joy to parents. Parents experienced many positive life changing events through parenting a child with autism. To help parents find that renewed sense of parenting, three strategies were expressed by parents: (a) cherishing the little things, (b) the importance of humour and patience, and (c) acceptance and preparation for the future. It was the child that enabled parents to get through each day, provided them strength and gave them hope for a bright future. When parenting a child with disabilities, cherishing the little things and embracing each milestone is well documented within the literature (Bayat, 2007; Glass, 2001; King, Zwaigenbaum et al., 2006; Ray, 2002; Woodgate et al., 2008). Parents in Bayat's qualitative study found that each success no matter how big or small impacted their day in a positive manor and despite the ongoing challenges that faced families with a child with autism; resilience became evident. Both Glass and Woodgate et al. found that it was those small moments and milestones that parents took extreme pleasure in and in turn, this allowed for joy and hope for the future. In addition to those small moments and milestones, affection and closeness, along with a sense of connection brought extreme happiness and joy for parents parenting a child with autism in this rural based study. Parents cherished these moments, enjoyed every accomplishment, bonded together as a family and never stopped learning from their child.

Learning patience was essential to the survival of parenting a child with autism in this study. Parents showed persistent patience for the child and their child's abilities. For parents in Cashin's (2004) study, parents believed that the development of patience was one of the positives in parenting a child with autism. Furthermore the importance of learning to laugh and using humour as a coping mechanism were described by parents in

this rural study. Laughing enabled parents to connect with their child and humour made the dark days lighter. Although there is no literature specifically looking at the importance of humour in parenting a child with autism, Scorgie and Sobsey (2000) found that parents of children with disabilities believed that “cultivating a sense of humour does help one maintain a sense of overall balance” (p. 201). Being able to laugh allowed parents in this study to get through the difficult times and feel a connection with their child, which in turn gave parents a renewed sense of parenting. Further studies in the area of laughter, patience and a renewed sense of parenting are warranted.

Parents never stopped believing in their child, but acknowledged that it may take longer for their child to accomplish their goals and dreams. Parents learned from their child and began to see the world differently than they ever imagined. According to King, Zwaigenbaum et al. (2006) parenting a child with Down syndrome or autism resulted in a life changing experience for the participating parents. Similar to this, Lauver (2008) found that foster parents of children with chronic illness experience a change of world views and values and Scorgie and Sobsey (2000) reported changes in parental perceptions of what was important and valuable in life.

Preparation for parents also extended to future planning and the transition into adulthood. This planning was fundamental in the ability for their child to be successful in all areas of life. Parental concerns for the future of children with disabilities are documented in the literature (Green, 2003; Little & Clark, 2006; MacDonald & Callery, 2007; Murphy et al., 2006; Vickers & Parris, 2005). Little and Clark showed how the transition into adulthood and the potential of independent living of children with Asperger’s and Nonverbal Learning Disorder were of great concern to parents. The

parents had concerns about the development of social and psychosocial maturity within their child and whether or not in the future their child would be able to live independently and find a partner. In addition, they worried how lack of resources and support systems would affect their child while they transitioned into adulthood. Similar to Little and Clark, parents in this study shared many of the same feelings. Concerns about the unknowns of autism and the possibility of independent living were revealed by many participants. Parents in this current study had mixed feelings about the future. Most parents described a one day at a time approach with a focus on the day to day living, with concerns about the future always in the back of their mind. Some parents began to put money aside for their child and accepted that their child may always need their assistance. Parents did their best to prepare for the unknown and the unexpected. Parents saw autism as an ability rather than a disability and wanted their child to be the best that they could be. Overall, parents embraced their child with all their strengths and weaknesses, cherished the little things, planned for the known and prepared for the unknown.

#### Parents' Recommendations to Professionals

Parents were asked about suggestions that they had for health care professionals and other professionals in regards to how they can best support parents of children with autism within a rural area. Parents were able to offer a variety of suggestions for professionals in how they can fulfill the needs of families. From diagnosis to everyday living and preparation for the future, families were involved in a lifelong journey and although things were improving in terms of services, there was still room for change. The first suggestion by parents was for rural physicians to really listen to parents. Parents had



legitimate concerns that often went unheard or unnoticed until something dramatic happened like a meltdown at the doctor's office or in a classroom. Parents in Dymond et al.'s (2007) study expressed similar concerns in regards to having professionals that were willing to listen and take parental concerns seriously. Early screening by public health nurses at immunization appointments was another recommendation by parents. Public health nurses could flag those children who were high risk for developing autism or other developmental disabilities. The literature reinforces that early diagnosis of autism is dependent on physicians listening to parental concerns (Committee on Children with Disabilities, 2001). Although parents in this rural study spoke of their developmental concerns about their child to rural physicians, diagnosis was still often delayed. This delay in diagnosis reinforces the need for physicians to listen to parents and take their concerns seriously.

Diagnosis was an unsettling time for parents and they spoke of the overwhelming feelings that occurred with all the information they were given at this time. Too much information given too early was a common concern from parents. Families needed time to comprehend the diagnosis before they were ready to take in all of the information. A second follow-up appointment with the developmental specialist would bring much comfort to these families. Timing the information given to parents, was key to successfully enabling these families.

Once back in their rural community, parents believed that rural physicians lacked the knowledge and understanding of autism and as well, lack the knowledge of where families were able to obtain appropriate help or available treatment programs. Additionally, parents expressed they would have benefitted from increased clinical hours

from speech, occupational and physical therapy. Parents expressed the need for increased professional support as communities often went for months to years with no specialized professional for the required services. Lack of appropriate professional support was evident throughout the interviews. Lack of trained respite workers was one of the greatest concerns voiced by parents. Furthermore, counselling services for parents, families, and adolescents with autism were severely lacking in rural communities. This lack of professional support and appropriate respite workers is documented within the literature in both rural and urban settings (Dymond et al., 2007; Norton & Drew, 1994; Scott-Findlay & Chalmers, 2001; Skinner & Slifkin, 2007). Specific to this study, parents wanted someone to talk to about coping with autism. Rural families went looking for counselling support and found none. Parent support networks and increased counselling or therapists would benefit parents and families who are parenting a child with autism.

Not only was there a lack of professionals in the rural community, there was a need for professionals to become more qualified and have increased experience with working with children who are diagnosed with autism. Increasing training for professionals and greater public awareness about autism would address these issues. Furthermore, increased collaboration between the array of professionals and within the school system was asked for by parents. The disconnection and lack of communication among primary caregivers, specialists, therapists and teachers is echoed by families in the studies by Dymond et al. (2007) and Lutenbacker et al. (2005). Treating autism required a multidisciplinary approach and professionals need to be open-minded to all possibilities. Early developmental intervention should be consistent and incorporate a variety of components that are individualistic to the child (Committee on Children with

Disabilities, 2001; Dymond et al.). Embracing technology was another suggestion by parents. Although telehealth is being used in some communities, not all were able to access and benefit from this service. Marcin et al. (2004) found that there was high satisfaction from rural parents and guardians who were able to use paediatric subspecialty telemedicine consultations. Furthermore, having conferences and presentations that were available online would greatly benefit parents that have difficulty with traveling and finding childcare.

### Conceptual Framework

This phenomenological study was directed by three major constructs. The operational definition of parent, rural area and meanings were provided within the first chapter. Defining these constructs allowed for the appropriate selection of data collection methods and guided the interpretation of data analysis to build upon the limited knowledge on autism and parents living in a rural setting. The Life Needs Model by King et al. (2002) served as the conceptual framework for this study. The model incorporates the need to return to parents themselves to explore their unique situation to determine what services were ideal for their context. Adapted for the multiple and changing needs for children with disabilities, their families, and surrounding community, the Life Needs Model attempts to determine the services required to support community participation and quality of life. The model aims to enable children to thrive in their community, rather than simply function. To gain the ultimate goal of community participation and quality of life, services programs throughout the child's life are required by communities. Unfortunately, according to parents in this study, many rural communities lack these vital services and families were often left with gaps.

King et al. (2002) identified five groups of services according to the types of needs of parents parenting a child with disabilities as determined by the literature. Services focusing on foundation skills are required as to allow the child to function in meaningful ways in their environment. Furthermore, the services required for the child to function confidently in real life settings are identified. These services are based on those building blocks of the foundational skills. Learning foundational skills is extremely important for children with autism. Specific treatment programs such as ABA, RDI and DIR/Floortime work on the basic foundational skills and enable the child to function in real life settings. Unfortunately, the rural parents in this study faced barriers with accessing these services. Financial barriers, lack of resources and lack of professionals all impeded parents' ability to obtain these services. However, services such as speech, occupational and physical therapy, although limited tended to be easier to access. The downside to living rurally, was that on average families were only receiving these services once a month. The third service program identified by King et al. was those services focusing on addressing the child's need for support and information. Providing support to the child throughout their life was crucial in achieving community participation and quality of life. The next group of services addresses parents' and family members' need for support. Ideal services included ways for parents to access to information about autism, services providing opportunities for social support such as parent support groups, and counselling services. For rural parents in this study, this service program group had room for improvement. Accessing information did not come easy for parents and most devoted great time and energy to finding everything they could about autism on their own. Although parent support groups were offered in some

communities and parents were notified of conferences and presentations, the time, energy and preparation required for parents to attend was not easily achieved. The final service group determined by King et al. encompasses the community members' need for information and education. Lack of knowledge of society was a significant downfall to parents in this study. This lack of understanding of autism by the community created a sense of isolation felt by families. Educating community members on autism would empower the community, dispel myths and foster opportunities for the child with autism (King et al.).

The Life Needs Model stresses that these services need to be a continuum of services to meet the changing needs of parents and children. Ongoing community education is warranted to help eliminate the physical, social and educational barriers to participation. Families in this study found that younger children with autism were able to participate more easily in things like preschool, daycare, swimming, and recreational activities such as going to the park. As the child aged, participation became more limited. Communities were able to offer areas for children to participate and although these activities incorporated inclusion, there was little understanding of autism and specific changes in the activity could not be made to foster full participation by these children. Lacking in communities was programs developed specifically to meet the unique requirement of children with disabilities.

The required needs as described by King et al. (2002) were also identified by parents in this study. The Life Needs model served as an appropriate conceptual framework for this study. Although the model is in its infancy, communities including those in rural areas would largely benefit from incorporating this model in addressing the

needs and services of parents and children with disabilities, including those with autism. Although rural communities had some of the identified services, multiple gaps remain and this model would aid in addressing those needs and therefore, increasing participation and quality of life for children with autism.

#### Methodological Limitations and Strengths

As with all qualitative research, this study has several inherent limitations and strengths associated with the design of the research. The following section reviews the study's limitations and strengths in regards to conceptualization, research design and research methods. Consideration of these limitations and strengths was employed during the analytical and interpretive stages of this study.

#### *Research Design*

Hermeneutic phenomenology research as described by van Manen (1990) was an appropriate philosophical framework for this study. As the aim of hermeneutic phenomenology is to explore human phenomena to understand the structure or essence of the lived experience (Dowling, 2007; Ray, 1994; Speziale & Carpenter, 2007), this research design was appropriate in exploring and describing the true meanings of rural parents' experience of parenting a child with autism. Hermeneutic phenomenology allowed the researcher to arrive at a thorough and accurate interpretation of the lived experience of the parents (Speziale & Carpenter). To understand a particular phenomenon, phenomenology research relies on the written word to understand the greater meaning. Through verbal interaction, the lived experience was shared to produce a narrative from which to comprehend the parents' original experience (Speziale & Carpenter). The experiences of the parents in this study were transformed into written

text and gave the researcher a rich language exploring the true meaning of parents' experience. Although there has been research detailing the stresses, challenges, coping mechanisms and lived experience of parents of children with autism, majority of this work involved urban parents. Lacking was research involving parents from rural settings. This is the first study to date, known to implement a phenomenological research design to uncover the experiences parents of rural communities ascribe to parenting a child with autism. In order to adequately meet the needs of these families, this research was crucial and essential. Furthermore, this study enlightened the fact that gaps still remain within the care of children with disabilities such as autism.

Generalization of the findings to all rural parents parenting a child with autism may not be possible due the inability of qualitative research to represent the broader population. However, in accordance to phenomenological research, there was no expectation that the findings of this study would be generalizable to all parents parenting a child with autism in a rural area. Furthermore, it was not expected that this study would be replicated to generate the same results; instead, it was believed that this research would result in new insights into the lives of rural parents of children with autism and in addition, form a foundation for future research.

Due to the cross-sectional design of this study with the data collected at only one point in time, it was impossible to know if parents experienced change over time. However, the sample of participating families included those of newly diagnosed children, those of school age children and those that had children in their teenage years which afforded more comprehensive understanding parents' experience across the autism trajectory.

Despite these limitations, the 26 families within this study provided a great representation of parenting a child with autism and resulted in new insights into the lives of rural parents of children with autism. Moreover, families represented 22 distinct communities in the province of Manitoba and therefore, furthermore, compensated for some of these limitations. In addition, several strategies were utilized to enhance credibility of the study. To ensure trustworthiness of the analysis, participants took part in a follow-up interview where they were asked to validate and clarify that the findings reflect their experience. All but one parent took part in the follow-up interview.

Throughout phenomenological research, the risk for potential bias is always present. To limit this bias, personal and theoretic assumptions and preliminary work were made clear by the researcher at the beginning of this study. In addition, a researcher's journal containing all attitudes, feelings and values towards rural families parenting a child with autism was kept through each step of the process. Observations were recorded; reflections and potential arising themes from the interviews in progress were kept. The purpose of this work was for the researcher to remain cognizant while collecting and analyzing the data so that the interpretation was a reflection of the parents' lived experience rather than that of the researcher's personal beliefs.

These experiences shared by the parents added and validated the findings found in the literature of parenting a child with a disability within a rural setting. These findings add to the parenting experience and moreover, assist in aiding health care professionals to provide the most optimal care to families parenting a child with autism in rural areas. In addition, these findings may be used to guide policy and program development concerned



with supporting the development of children with autism as well as improving the health and quality of families of children with autism.

### *Research Methods*

van Manen's six methodological themes (see Table 1) were used to address and direct the purpose of this study and guide the data collection, analysis and interpretation and furthermore, focused the direction of this study. Exploring the phenomenon as parents' lived it, reflecting on essential themes through reading and re-reading followed by writing and analyzing the participants' experience enabled a deep understanding of the meanings parents assigned to parenting a child with autism in a rural community.

A total of 51 interviews from 26 participating families were completed. Although 26 is not a large sample size, the intent of the number of participants was not to generalize, but rather to obtain information-rich cases to arrive at an in-depth understanding of the phenomenon (Patton, 1990; Sandelowski, 1995; Speziale & Carpenter, 2007). Furthermore, Ray (1994) stressed that the selection of participants based in hermeneutic phenomenology are those that are involved in a similar experience to capture the true meaning. In qualitative research, data collection occurs until saturation is achieved and therefore, there are no definite rules for the ideal sample size (Speziale & Carpenter). All 26 interviews were analyzed and data saturation was achieved and shown through the repetition of essences and themes.

A greater number of female participants were represented in this study; however it was important to seek out the primary care giver which often falls upon the mother and therefore, not surprising that there would be mostly female participants. Although the purpose of purposive sampling was to invite the primary caregiver, having a sample

consisting mostly of mothers may limit findings. This is consistent with the literature as mothers are normally the primary caregiver (Statistics Canada, 2004) and unfortunately many of the studies exploring parenting a child with disabilities primarily were from the experiences of the mother (King, Zwaigenbaum, et al. 2006; Murphy et al., 2006; Ray, 2002; Woodgate et al. 2008) or just included mothers (Larson, 1998; Vickers & Parris, 2005). Nonetheless, there was variety found within the ages of the participants, material status and educational background. The inclusion of two single fathers added to the richness of the data and may have revealed additional information about parents' lived experience. This further warrants the need for studies to include fathers or significant others within the research.

Since autism tends to affect boys three to four times more likely than girls (Committee on Children with Disabilities, 2001), there was a slight overrepresentation of boys within this study however, diversity was shown through the variety of ages of the children, the age of diagnosis, and the range of abilities/impairments. Regardless of this diversity, the meanings ascribed to parenting a child with autism in rural Manitoba remained the same. Beside those families involved with ABA through St. Amant, families within the Eastman region were not sent out invitations due to staffing reasons at CSS. These families may have had important insights to parenting a child with autism but were excluded because they were unaware of the study. In addition, some families, although they lived rurally, were able to access services from the City of Winnipeg and therefore, may have different experiences in regards to services and participation.

## Recommendations

Results from this study, allows for the consideration of future directions for those in the professional field including nursing. Further research recommendations are also warranted. Recommendations for professionals evolving from the study are now presented in the form of practice and education and research.

### *Practice and Education*

Follow-up support for rural families needs to be addressed by professionals. Support is especially warranted in the immediate time period after initial diagnosis and follow-up to assess coping strategies and needs should be mandated. Children living in rural areas diagnosed with autism need to be reassessed regularly so that the services they require are appropriate to enable the best quality of life. Additionally, rural nurses and other health care and social service providers should be assessed on their level of knowledge of autism and be provided with opportunities to further their knowledge and obtain strategies to enhance the lives of parents parenting a child with autism. Educating health care professionals, families, friends and communities who lack the knowledge of autism should be top priority to enable the understanding of what autism means to the parents and the demands that it places on daily life.

Professionals, especially rural physicians, need to be aware of the concerns, needs and meanings that parents give to parenting a child with autism in rural settings. Rural physicians need to be aware of what is available within their community, what type of options are out there and what new advances and progressions are being made in the field of autism. Nurses and other health care and social service providers need to understand that parents know their child best and that they need to listen to parents and validate their

concerns. Collaboration between health care professionals is crucial as well as being open-minded to the different treatment options and types of support available. Health care professionals need to be able to provide information to parents about autism as it is these professionals that parents turn to when they are lost and need direction.

Furthermore, Public Health Nurses in Manitoba should complete a screening at immunization appointments and flag those children who are at high risk of developing autism. Increased education and training on autism and developmental milestones is also warranted for all nurses, especially those in primary health care.

Special attention needs to be given to rural communities that are of greater distance away from an urban centre as services and health care professionals are dramatically reduced and where much onus is placed on the parents to obtain everything for their child. Attraction and retention of health care professionals is another area of concern for small rural communities and this needs to be addressed. Additionally, increased technology such as telehealth, video conferences and the Internet should be used more frequently to disperse knowledge and education in regards to autism to parents, health care professionals and communities.

### *Research*

Published literature on rural parents parenting a child with autism was not found and future studies are warranted to validate the findings from this study. As well, additional research on living rurally and parenting a child with disabilities would be beneficial as this literature is very limited. Research addressing rural families' experience of those living greater distances from an urban city compared to those who live closer is warranted as potential differences were noted within this study. Furthermore, research in

all area of parenting children in terms of services and participation in rural communities is needed. Research describing the positive attributes of living rurally and reasons why parents continue to live in a rural community while parenting a child with disabilities is warranted. Increasing the number of father participants is fundamental in all future parenting studies as well as looking comparison studies between mothers and fathers lived experience would be beneficial. Moreover, research understanding the knowledge level and experience that rural health care providers have about autism would identify gaps in the field of autism. Research addressing recruitment and retaining of professionals in rural settings, will help communities obtain equality of services for all families parenting a child with autism.

#### Chapter Summary

Many of the experiences shared by parents in this study echo those found in the literature. Unfortunately majority of this literature is based on parents parenting a child with disabilities and not just those parenting a child with autism. Making the invisible, visible emerged as the essence of parents' experience and this has been documented in the literature in regards to parenting a child with disabilities. Further validation of this study is warranted as there is limited research exploring the lives of parenting a child with autism. The rural aspect of this study makes it the only known phenomenological study describing the experience of parenting a child with autism in a rural community. Recommendations by parents for health care and other professionals were provided and the conceptual framework was discussed. Methodological limitations and strengths were discussed in terms of research design and methods. In conclusion, recommendations for practice and education and future research were provided.

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Appendix A: Letter of Invitation



Faculty of Nursing

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Dear Parent

My name is Lindsey Hoogsteen, and I am a paediatric nurse and student in the Master of Nursing program at the University of Manitoba. This letter is being sent to you on my behalf by the ABA Program at St. Amant/Children Special Services. I do not know your name or have any information about you or your family.

To complete my nursing program, I am doing a thesis about *the lived experience of parents in rural areas who are parenting a child with autism*. I would like to explore the day-to-day living with parents parenting a child with autism. I want to discover what meanings rural parents attribute to parenting a child with autism and uncover what recommendations rural parents have for health professionals in order to best support their family. Dr. Roberta Woodgate of the *Faculty of Nursing at the University of Manitoba* is my advisor for this study. My thesis has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba [and the research board at St. Amant].

In order to complete my thesis, I would like to interview yourself and other parents who are raising a child with autism and live in a rural setting. The interview should take approximately one to two hours to complete. A second interview will take place to validate the information from the first interview and for you to offer any further information. This second interview should only last 30 minutes to one hour and may be done over the phone. If you so wish, you may decline to participate in the second interview.

Once all interviews are completed, I will compile all gathered information from your interview and the interviews of other families and compose my thesis highlighting the findings. All identity of the families will remain confidential throughout the entire study and will never be revealed or discussed with anyone. This paper will be shared with other health care professionals so that they may further learn from your experiences and expand their knowledge of autism. If you wish, you will have the opportunity to receive a summary of the study.

If you are interested in hearing more about this study, please contact myself directly or return the enclosed form in the self addressed stamped envelope. I will then explain the study in further detail and answer any of your questions. If you decide to

participate, I will set up an interview time and place convenient for you. If you decide not to participate, you can say no without any consequences. Participation throughout this study is completely voluntarily and you may stop at any time.

Thank-you for your time and consideration of this study.

Sincerely,

Lindsey Hoogsteen, MN Student

Appendix B: Telephone Script



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Hello \_\_\_\_\_

My name is Lindsey Hoogsteen and I am a master of nursing student at the University of Manitoba. I have received your invitation to participate and I am now calling to inform you further about the study in hopes to confirm your participation.

I am interested in learning more about families' experiences with parenting and living with a child with autism; especially important to me are those families that live in rural settings. The research will provide insight into how parents live, see and interpret the daily life of raising a child with autism. Unfortunately, there is very little written information on families who have a child with autism and there is nothing published on families living in a rural area. As a paediatric nurse, I feel that nurses and other health care professional that care for families and children with autism would benefit tremendously from learning all we can about this unique experience. Although every family has an individual parenting experience, it is hoped that your shared experiences will help health care professionals and other families understand that they are not alone in this lifelong journey of autism. Overall, this study will result in new insights into the lives of rural parents of children with autism. Findings from this study may be used to guide program development that is concerned with improving the development of children with autism, as well as the health and quality of life of parents of children with autism.

In the process of this study, I will be conducting interviews with a parent or parents of a small numbers of families living within a rural setting. The interview should take approximately one to two hours to complete and will be tape recorded as to not miss out on any important information. If you are willing, a second interview (which may be done by phone) will be completed in order to validate the collected information and for you to have the chance to add any other information you feel beneficial.

All interviews will be typed out and read. Common thoughts, feelings and themes will be extracted and compiled. Although I will be the only person knowing the identity of each interviewee, Dr. Roberta Woodgate, my advisor for this study, will also read and have access to the typed out interviews. All names will be given code numbers in order to maintain confidentiality. All material, including tapes and written data will be stored in a secured place and one year after completion of the study, all material will be destroyed.

This research project is being done in order to fulfill the requirements of my thesis. It is my intention to take the information that I collect from this study and publish an article in a professional journal. Confidentiality will be maintained throughout the entire process and your name or identity will never be released. Upon request, you will have the opportunity to receive a summary of this study.

Once you agree to participate, you are free to withdraw from the study at any point of time without any consequence. You may also choose not to answer questions or stop the interview whenever you wish. Do you have any questions regarding this study? Would you be willing to participate?

If “No”: Thank you very much for your time and consideration of this study.

If “I would like to think about it”: Thank-you for your consideration. When should I call you back to find out about your decision?

If “Yes”: Thank you for your participation. When would be a good day and time for you to schedule the first interview? Would you like for it to take place in your home?

If “No”: Where would you like to conduct the interview?

At the first interview, I will be asking you to sign a consent form saying that you will participate based on the information that has been provided to you. You will also be asked to fill out a short form so I may get to know your family better. In order to prepare for the interview, it may be beneficial to think about your thoughts, feelings and experiences and any events or decisions that stand out in your mind. My goal is to find out all about parenting a child with autism while living in a rural area.

Thank-you for your time. I look forward to seeing you on \_\_\_\_\_ at \_\_\_\_\_.

## Appendix C: Interview Guide



### Faculty of Nursing

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#### Introduction to the Interview

I would like to learn more about what it is like to raise a child with autism, especially what it is like to while living in a rural setting. I would like for you to share your experiences from the time prior to your child's diagnosis to the present period. It would be beneficial for you to explain your thoughts and feelings, what it is like to parent a child with autism, your parenting styles, the challenges and opportunities you experience, the types of needs you have, the available support or the support that was unavailable, the help you received, ways that you were able to cope and anything else that comes to mind.

Note: Probes will only be used as necessary to elicit further discussion.

1. Tell me about life prior to when your child was diagnosed with autism.
  - a. What was the day-to-day like for your family?
  - b. What was the day-to-day life like for your child with autism?
    - i. How was your child able to participate?
    - ii. In daily life?
    - iii. Within your community?
  - c. What was the day-to-day life like for you as a parent?
  - d. How did you parent? Did you care for your child differently?
  - e. Tell me about some good experiences or joys that you had being a parent during this period.
  - f. Tell me about some difficult times or challenges you faced being a parent during this period (i.e. communication? behaviour ?)
  - g. What types of needs did you have at this time?
  - h. Tell me about any experiences in which you needed support or help in parenting your child during this time.
  - i. What types of things did you do to cope? (i.e. family support? religion? friends? family? doctors?)
  - j. How did living in a rural area affect your daily life?
  - k. Were there any feelings of isolation?
  
2. Tell me what life was like after your child was diagnosed with autism.
  - a. How did you cope with the diagnosis of autism? (What was your reaction? – how did you feel?)

- b. Did you tell people about the diagnosis? What was their reaction?
  - c. What was the day-to-day life like for your family? – Did you have to rearrange your home? Rearrange your life?
  - d. What was the day-to-day life like for your child with autism?
    - i. How was your child able to participate?
    - ii. In daily life?
    - iii. Within your community? (How did your community take to the diagnosis of autism?)
  - e. What was the day-to-day life like for you as a parent?
  - f. How did you parent? Do you feel that your parenting changed from before diagnosis?
    - i. If so, how did it change?
  - g. Tell me about some good experiences or joys that you had being a parent during this period.
  - h. Tell me about some difficult times or challenges you faced being a parent during this period.
  - i. What types of needs did you have at this time?
  - j. Tell me about any experiences in which you needed support or help in parenting your child during this time. What types of things did you do to cope?
  - k. How did living in a rural area affect your daily life?
3. Tell me about what life is like for you and your family now.
- a. What is day-to-day life like for your family?
  - b. How is your child being able to participate?
    - i. In daily life?
    - ii. Within your community?
  - c. How do you parent now? Has it changed from previous? How is your relationship with your partner?
  - d. Do parents of children with autism parent differently than parents of children without autism?
  - e. Tell me about some good experiences or joys that you have being a parent at this time in your life.
  - f. Tell me about some difficult times or challenges you face being a parent during this time in your life.
  - g. What types of needs do you have at this time? Is it hard to meet these needs? (navigate the system?)
  - h. Tell me about any experiences in which you needed support or help in parenting your child during this time in your life?
  - i. What types of things do you do to cope?
  - j. How do you see things for the future? Concerns? Fears?
  - k. How does living in a rural area affect your daily life at this time in your life?
4. Overall what is your philosophy of parenting? Has this changed over the years?

5. Based on your experiences, what advice would you give to other parents who are raising a child with autism in a rural area?
6. What suggestions would you have for health care professionals and other professionals about how they can best support parents of children with autism?
  - a. Do you feel that parents and professionals understand the needs of parents of a child with autism? Of families living in a rural area?
7. Is there anything else you would like to talk about that you feel is important for me to know?
  - a. Are there any additional questions which you think I should be asking during this interview?
  - b. Are there any issues/areas which we have not covered which you think we should?



Appendix D: Family Demographic Profile



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ID#: \_\_\_\_\_

Date: \_\_\_\_\_

Information on this form will help me get to know you and your family better. All information collected will remain confidential.

1. How many children do you have in your family: \_\_\_\_\_

Age	Sex	Grade Level/Daycare

2. For Two-Parent Families:

Are you married: Yes \_\_\_\_\_ No \_\_\_\_\_

Are you living together: Yes \_\_\_\_\_ No \_\_\_\_\_

Other: \_\_\_\_\_

For Single-Parent Families:

Have you ever been married: Yes \_\_\_\_\_ No \_\_\_\_\_

Are you separate: Yes \_\_\_\_\_ No \_\_\_\_\_

Are you divorced: Yes \_\_\_\_\_ No \_\_\_\_\_

Are you widowed: Yes \_\_\_\_\_ No \_\_\_\_\_

3. How old are you (or the both of you):

Yourself: Sex \_\_\_\_\_ Age: \_\_\_\_\_

Partner: Sex \_\_\_\_\_ Age: \_\_\_\_\_

4. What is your ethnic background:

Mother: \_\_\_\_\_ Partner: \_\_\_\_\_

5. What is your occupation (Please check appropriate box):

<b>Mother</b>		<b>Partner</b>	
Clerical		Clerical	
Retail		Retail	
Laborer		Laborer	
Professional		Professional	
Management		Management	
Homemaker		Homemaker	
Retired		Retired	
Other (please specify)		Other (please specify)	
N/A		N/A	

6. What is your highest level of education (Please check the appropriate box):

<b>Mother</b>		<b>Partner</b>	
Grade 8 or less		Grade 8 or less	
Some high school		Some high school	
High school diploma		High school diploma	
Some college		Some college	
College degree		College degree	
Some university		Some university	
Bachelor's degree		Bachelor's degree	
Master's degree		Master's degree	
PhD		PhD	
N/A		N/A	

7. What do you live in:

House: \_\_\_\_\_

Apartment: \_\_\_\_\_

Other: \_\_\_\_\_

8. Approximately how many kilometers are you from Winnipeg: \_\_\_\_\_

a. How long have you lived here: \_\_\_\_\_

**Questions 9 through 17 are specific to your child with autism (Additional forms are available for families with more than one child with autism):**

9. When was your child born: \_\_\_\_\_

10. At what age was your child diagnosed with autism: \_\_\_\_\_

11. Does your child have any additional diagnoses: Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, please describe: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

12. Is your child on any medication: Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, please describe: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

13. What levels of assistance does your child with autism need in daily living activities (Please check the appropriate box):

	No Assistance	Minimum Assistance	Moderate Assistance	Extensive Assistance
Toileting				
Eating and drinking				
Bathing				
Grooming				
Dressing				
Communicating				
Playing				

14. Does your child receive any of the following services? If so, please identify the number of hours per week.

Type of Service	Approximate Number of Hours per Week
Physical Therapy	
Occupational Therapy	
Speech Therapy	
Counselling	
Teacher's Assistant	

15. Are you currently involved in any type of treatment program: \_\_\_\_\_

If Yes: What type of treatment: \_\_\_\_\_

If No: Have you ever been: \_\_\_\_\_

If Yes, what type and for how long: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

16. Do you receive any of the following services that help you care for your child? If so, please identify the number of hours per week.

Type of Service	Approximate Number of Hours per Week
Respite Services	
Home Nursing	
Transportation	
Family Members/Neighbours/Friends	
Other:	

17. Do you and your child(ren) attend/receive any of the following support services:

<b>Support Groups/Networks</b>	<b>If yes, what one</b>
Parent Network	
Peer Network	
Newsletter	
Advocacy Group	
Other:	

18. Is there anything else you would like to tell me about yourself or your family?

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**Thank-you for your assistance in helping me understand and learn more about the needs and experiences of families that have a child with autism and who are living in a rural area.**



UNIVERSITY  
OF MANITOBA

Faculty of Nursing

Faculty of Nursing  
Helen Glass Centre for Nursing  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone: (204) 474-7456  
Fax: (204) 474-7682

**For families that have more than one child affected by autism.**

1. When was your child born: \_\_\_\_\_
2. At what age was your child diagnosed with autism: \_\_\_\_\_
3. Does your child have any additional diagnoses: Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, please describe: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

4. Is your child on any medication: Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, please describe: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

5. What levels of assistance does your child with autism need in daily living activities (Please check the appropriate box):

	No Assistance	Minimum Assistance	Moderate Assistance	Extensive Assistance
Toileting				
Eating and drinking				
Bathing				
Grooming				
Dressing				
Communicating				
Playing				
Other:				

6. Does your child receive any of the following services? If so, please identify the number of hours per week.

Type of Service	Approximate Number of Hours per Week
Physical Therapy	
Occupational Therapy	
Speech Therapy	
Counselling	
Teacher's Assistant	
Other:	

7. Is your child you currently involved in any type of treatment program:

\_\_\_\_\_

If Yes: What type of treatment: \_\_\_\_\_

If No: Has your child ever been: \_\_\_\_\_

If Yes, what type and for how long: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

8. Do you receive any of the following services that help you care for your child? If so, please identify the number of hours per week.

Type of Service	Approximate Number of Hours per Week
Respite Services	
Home Nursing	
Transportation	
Family Members/Neighbours/Friends	
Other:	

Appendix E: Consent Form



Faculty of Nursing

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**Research Study Title:** *The Lived Experience of Parenting a Child with Autism in a Rural Area*

**Study's Investigators:**

1. Lindsey Hoogsteen, RN, Graduate Student, Faculty of Nursing, University of Manitoba
2. Dr. Roberta Woodgate, Faculty of Nursing, University of Manitoba, Advisor
3. Dr. Christine Ateah, Faculty of Nursing, University of Manitoba, Internal Committee member
4. Dr. Kathryn Levine, Faculty of Social Work, University of Manitoba, External Committee member

**This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involved. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.**

I, \_\_\_\_\_, agree to participate in the above study. I have been told that the purpose of this study is to explore the parenting experiences of families raising a child with autism that live in a rural setting. The day-to-day living of parenting a child with autism will be explored. The meanings that I attribute to parenting a child with autism and the recommendations that I have for professionals in order to best support my family and other families parenting a child with autism will be determined. I understand what is learned from this study will be used by professionals who work with parents of children with autism and are concerned with improving their health and quality of life.

I understand that if I agree to participate in the study, I will be asked to participate in two open-ended audio taped-recorded interviews. I understand that the Master of Nursing student, Lindsey Hoogsteen under the supervision of Dr. Woodgate will be doing the interviewing for the interviews. I understand that I will be asked questions related to the day-to-day living of parenting my child with autism. I understand that the first interview will take one to two hours and will be tape recorded for further analysis and



interpretation with the second interview lasting 30 minutes to one hour. I also understand that I may decline the second interview if I do not wish to be interviewed again. I understand that I will be asked to complete a Demographic Form prior to being interviewed. This form should take approximately 10-15 minutes to complete. During the interview, the interviewer will be taking field notes to describe her observations, reflections and potential arising themes. These notes will be kept confidential except to be shared with her advisor to aid in analysis of the data.

I understand that my participation in this study is completely voluntary. I understand that even if I decided to participate, I may withdraw at any time and refrain from answering any questions, without prejudice or consequence by telling Lindsey Hoogsteen. As well, the information that I have provided will not be included within the study.

I understand that there are no direct benefits for me or my family to participating in the study. However, I understand that this study will result in knowledge that may help professionals increase the quality of life for children diagnosed with autism. I understand that there are no undue risks to me by taking part in the study. I understand that I will receive an honorarium for participating in this study. I understand that even if I decide to withdraw from this study I will still receive the honorarium.

I understand that findings from this study may be presented at a health or educational conference or published in a professional journal. In all instances, my or my family's identity would not be discussed or revealed to anyone. Only Lindsey Hoogsteen, the study's researcher will have access to our names. As well, I understand that in all instances, our names and identities would not be discussed or revealed to anyone. I am aware that my name will be replaced with a code number so that no one will be able to identify me. I understand that only Dr. Woodgate and Lindsey Hoogsteen will have access to the interviews. I understand that confidentiality will be maintained except in situations in which there is a legal requirement to disclose identity (i.e., abuse situations). I understand that all data including the audiotapes, pictures, interview transcripts, field notes, and demographic information will be stored in a locked filing cabinet within the researcher's home and computer protected by a password known only to Lindsey Hoogsteen. I understand that all data will be destroyed following one year after completion of the study. I understand that if I decide to participate in the study, a summary of the study will be provided to me if requested.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive my legal rights nor release the researchers, or involved institutions from their legal and professional responsibilities. I understand that my and my family's continued participation should be as informed as my initial consent, so I should feel free to ask for clarification of new information throughout my participation. I understand this research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba. If I have any concerns about this project I may contact Dr.

Woodgate at (204) 474-8338 or the Human Ethics Secretariat at (204) 474-7122. A copy of this consent form has been given to me to keep for my records and reference.

I agree to take part in the first interview. Yes \_\_\_\_\_ No \_\_\_\_\_  
I agree to take part in the second follow-up interview. Yes \_\_\_\_\_ No \_\_\_\_\_

\_\_\_\_\_  
Signature of Parent/Guardian                      Print Name of Parent/Guardian                      Date

\_\_\_\_\_  
Signature of Witness                      Title                      Print Name of Witness                      Date

I would like a summary report of the findings (Please Check):

Yes	_____
No	_____

Please mail a summary of the report findings to:

Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Postal Code: \_\_\_\_\_