

**Rural Services for Children with ADHD:  
The Experiences of Parents**

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A practicum project submitted in partial fulfilment of  
The requirements for the degree of Master of Nursing

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**BY**

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of  
Manitoba in partial fulfillment of the requirement of the degree  
Of  
MASTER OF NURSING**

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## Abstract

Attention deficit/hyperactivity disorder (ADHD) is a common condition affecting approximately 5-7% of children across North America. ADHD is characterized by inattention and impulsivity. Conflicting relationships with family and peers present further problems. The nature of this condition is a challenge for parents, teachers, society and families.

Experts in the area have raised concerns that inadequate care of the child with ADHD can lead to serious problems and family dysfunction. Quality care for the child with ADHD and their family has been shown to reduce family stress, improve the child's functioning and academic achievements and reduce potential for co-morbidity and emotional problems later in life.

Anecdotal reports suggest that the quality of care for children with ADHD may be lacking in the health care system, particularly in locations with minimal resources. A review of national and international literature reveals that the parents of children with ADHD often have to function as the coordinators of care or as advocates for their children. This suggests the system is fragmented. The care and services required are difficult to acquire, particularly within the school system.

The purpose of this study was to arrive at a beginning understanding of parents' experiences regarding the care of their children with ADHD in a rural setting. The questions presented to parents in this study include; 1) What do rural parents see as the main care needs for their children with ADHD? 2) What are rural parents' perspectives of the services and resources presently provided to meet the care needs of their children with ADHD? 3) What recommendations do rural parents have about how to improve the system of care for their children with ADHD?

Six parents and one grandparent were interviewed using a semi-structured interview process. Data were analyzed by summarizing highlights of responses to each interview question. Key

findings reveal general dissatisfaction with the rural system of care. Parents indicated that ADHD is a condition that requires recognition and intervention by both the system and communities in which they reside. Parents indicated that once their child was labeled as a 'problem,' it was very difficult for the child and family to find adequate supports especially within the school system. Lack of access to appropriate services and crisis assistance was identified as a serious concern in the rural setting. Based upon the findings of this study, recommendations for future directions in research and practice are identified.

## Chapter One: Introduction

This chapter contains a review of the literature highlighting the significance of ADHD in Canada and Manitoba. The literature review covers information on the diagnosis, care and services for children with ADHD. Some discussion takes place about treating ADHD in rural systems and the primary care setting in the present day. An analysis of available literature looking at the perspectives of parents (particularly mothers) is provided. Finally, a look at ADHD in Manitoba, based on the review of the limited amount of available literature and interviewing some key contacts relevant to the rural system of care, will be presented.

Attention deficit/hyperactivity disorder (ADHD) is a childhood mental health disorder characterized by inattention, impulsiveness and over activity (Diagnostic Statistical Manual (DSM) IV, 1994). It is the most common childhood disorder across the USA and Canada with reported incidence varying from 2-12%. There is uncertainty regarding the true incidence as discussed in the literature with many speculating over diagnosis and some touting under diagnosis (Rushton, Fant & Clark, 2004; Wender, 2002). A Canadian longitudinal study looked at the incidence of hyperactivity-impulsivity and inattention based on mothers' responses. It was found that between 5% and 17% of 2-11 year-old girls and between 9% and 23% of 2-11 year-old boys *often* manifested hyperactive-impulsive behaviours and that between 1% and 18% of 2-11 year-old girls and between 1% and 14% of same-aged boys *often* manifested inattentive behaviours (Romano, Baillargeon & Tremblay, 2002). Generally, most studies report an overall incidence of 5-7%, with boys outnumbering girls up to 9:1 (Frazier & Merrell, 1997). ADHD-related symptoms are the most common constellation of problems in children with behaviour issues who are referred for treatment to clinical and specialized educational programs (Frazier & Merrell, 1997; Polaha, Cooper, Meadows & Kratochvil, 2005). The incidence of ADHD appears to be rising which has fueled controversy about the subsequent increase in medication use and

about the appropriateness of the services these children receive. There is some speculation that increased familiarity and acceptance of the condition by medical professionals have boosted the numbers of diagnosed children. ADHD is a chronic condition often extending into adolescence and adulthood (College of Physicians and Surgeons of Manitoba, 2001; Canadian Pediatric Society (CPS), 2002) and if not treated early and appropriately, may impair the development of the affected child (G. Bobowski, The Learning Disabilities Association of Manitoba (LDAM) Intake and Workshop Coordinator, personal communication, August, 2005; Sloan, Jensen & Kettle, 1999; Teisl, Mazzocco, & Myers, 2001). ADHD results in high costs in terms of utilization of services in primary care, outpatient mental health and pharmacy and coexisting conditions significantly increase these costs (Guevera, Lozano, Wickizer, Mell, & Gephart, 2001)

ADHD is a condition that is pervasive, meaning that it is present in more than one aspect of the child's life including school, home and social activities (DSM IV, 1994). This condition has impact on the child's surroundings including parents (particularly mothers), teachers, classmates and the ADHD child's siblings related to the disturbed and conflictual nature of interactions and with more negative behaviours than normal, same-age counterparts (DSM IV, 1994; Wells et al., 2000). To complicate things further, there are co-morbid conditions that often accompany this disorder. Academic underachievement is common with findings that up to 70% of children with ADHD have some form of learning disability (Marshall, Hynd, Handwerk, & Hall, 1997; Mayes, Calhoun, & Crowell, 2000; Molina & Pelham, 2001). In addition, other conditions commonly accompany ADHD such as oppositional defiance disorder and conduct problems (Snyder, Prichard, Schrepferman, Patrick, & Stoolmiller, 2004), crime and substance abuse (Fergusson, Swain-Campbell, & Horwood, 2002; Lambert & Hartsough, 1998; Molina & Pelham, 2001; Weinberg, 2001), deviant peer afflictions (Fergusson et al., 2002) and other psychiatric



conditions such as depression or anxiety (Crist, 1999). This disorder presents significant challenges to schools, families and primary care providers (PCP) with respect to the child's ability to function, particularly in school.

Children with ADHD are often very difficult to parent due to oppositional behaviour, high-risk behaviours, excessive sibling rivalry and at-home conflict (Frazier & Merrell, 1997). Often parents feel unsupported even by family and friends since very few individuals and even health care providers have an understanding of this condition. It is easily mistaken by the schools and/or social community as "bad parenting" and the parents receive blame or are disgraced for their "lack of effective discipline." Controversial issues that are often in the media regarding diagnosis and treatment complicate the image of ADHD. These controversies make it difficult for parents, medical providers and schools especially when there is a lack of public acceptance and understanding of the condition resulting in stigma of the child and often their family.

The definition of a child with ADHD for the purpose of this project will include any child diagnosed regardless of the criteria used. Attention deficit disorder sub-types described in the DSM-IV divide the disorder into hyperactive, non-hyperactive (inattentive) or combined types (DSM IV, 1994). In the literature, the key differentiating characteristics between subtypes is the potential risk for certain co-morbid conditions. However, the various subtypes are not generally believed to require different treatment or monitoring (Saklofske, Schwean, & Burt, 1999), therefore attention deficit/hyperactivity disorder (ADHD) will be referred as one broad entity for the purpose of this project.

### *Care and Services*

Combinations of behavioural therapy and stimulant drug therapy have demonstrated the most efficacy in the treatment of ADHD (Klein & Abikoff, 1997) and are the two primary interventions. Much research demonstrates that ADHD is a neurobiological disorder with pre-

frontal cortex defects and evidence of a genetic predisposition (Anderson, 2002; Biederman, & Spencer, 2000; Levy, Hay, McStephen, Wood, & Waldman, 1997). Despite the physiologic cause, environmental and behavioural interventions have been effective in improving the symptoms of ADHD although they need to be continuous to maintain treatment effect (Chronis, Chacko, Fabiano, Wymbs, & Pelham, 2004; Frazier & Merrell, 1997). Research has shown that effective treatment for ADHD must include working directly with parents to modify their parenting behaviours to increase positive outcomes in their children (Pelham, Wheeler & Chronis, 1998; Multimodal Treatment Study for Attention-Deficit Hyperactivity Disorder (MTA) Cooperative Group, 1999). Stimulant therapy reduces the primary ADHD symptoms (American Academy of Pediatrics (AAP), 2001) thus reducing negative parental responses. Teaching parents behavioural interventions promotes positive parenting behaviours that result in improvement of ADHD behaviours and thus lowers parenting stresses and marital conflicts (Wells et al., 2000). Educating parents regarding the potential side effects of stimulant medication and the expected therapeutic response minimizes worry and encourages compliance (K. Weibe, Clinical Psychologist, personal communication, July 14, 2005). There is evidence that the benefits of ADHD treatment far outweigh the risks. Children with ADHD tend to lack the impulse inhibition and executive function that would normally allow them to realize that there are consequences for their actions. Not only has it been shown that the proactive use of ADHD medications in children may prevent addictions and emotional problems later in life (Adler, Biederman, Dodson, & Findling, 2005), but that some of the dangers of untreated ADHD can be avoided such as motor vehicle accidents and risk-taking behaviours (Biederman, Faraone, Manuteaux, & Grossbard, 2004).

There is general agreement that the most effective treatment for ADHD is primarily composed of stimulant and behaviour therapies. However, the care of children is complex and

time consuming as every family and child with ADHD is unique and requires highly individualized care plans. This is necessary to adapt to variability that will assure a quality service (Frazier & Merrell, 1997), and to take into consideration both environmental and developmental information (Halasz & Vance, 2002). The literature recommends that a variety of providers be involved to assure comprehensive care (AAP, 2001). Without teamwork, there is potential variance in the information and advice provided to families that may be confusing for parents. Not only is the variance between providers confusing, there are numerous pharmacologic and non-pharmacologic therapies that are controversial regarding their efficacy (CPS, 2002a; Halasz & Vance, 2002; Livingston, 1997; Wender, 2002) and safety (Schachter, King, Lanford, & Moher, 2001). This potentially creates a situation where the parents do not know how much or what type of care their child with ADHD needs or “should have.” The endless claims of alternative “miracle cures” for ADHD on the internet and in the media add to the confusion especially for parents and PCPs when it comes to decision-making regarding treatment and management.

The literature demonstrates that a common contributor to non-diagnosis or poor management of ADHD is the lack of appropriate health care professionals (Manitoba Health Research Council, 2001; Miller, Lalonde, McGrail, & Armstrong, 2001). It is expected that these challenges are more prominent in rural settings such as those in Manitoba where there is a lack of specialized services such as mental health, speech therapy and specialized education (K. Weibe, 2005, personal communication, July 14, 2005). Services for children with ADHD are hampered by what is “missing” from the system such as parent support, parent education, parent training and social skills groups (Hazelwood, Bovingdone, & Tiemens, 2002). The parents and their children with ADHD in the rural locations often have to commute to urban centres to access

needed services. Families' socioeconomic status and access to a means of transportation affect their ability to access specialized services.

The health of children with ADHD and their families is impacted by a lack of specialized services. Peer, school, family relations, growth and development level, social skills, and level of control of symptoms such as impulsivity and disruptive behaviour are measures of the health of children with ADHD. The subjectivity of these measures makes it difficult to monitor progress and intervention effectiveness in these areas. There appears to be a prominent focus on symptom reduction in the literature and little research was found on the effects of ADHD on other aspects of the child's health. One study looking at the quality of life (QOL) in children has shown that ADHD has significant impact on multiple domains of QOL and researchers have found significant parent-reported problems in terms of emotional-behavioural role function, behaviour, mental health, and self esteem (Klassen, Miller, & Fine, 2004). ADHD care guidelines recommend using rating scales to monitor treatment success in children with ADHD (AAP, 2001) which are useful in that they give an objective "rating" or score to each measure of the child's success that is helpful since most measures are subjective in nature and difficult to quantify. However, the study on QOL demonstrates that there are more outcomes to monitor in children with ADHD than can be accomplished through rating scales alone. This reinforces that in order to improve the overall health and functioning of these children, one should consider the impact of symptoms and associated disorders. This reinforces that one guideline or standardized rating scale providing a 'cookie cutter' service may not be appropriate (Halasz & Vance, 2002) and that service provision and decisions about needed support should incorporate a broader range of functionally relevant indicators (Klassen et al., 2004). In addition, Klassen et al. (2004) found that important predictors of QOL were the presence of co-morbid psychiatric disorders. Studies

have shown that early and consistent interventions and close monitoring improve self-esteem and QOL in children with ADHD (Lavoie, 1998).

Few studies define the frequency of monitoring required for children with ADHD to assure quality care. Stimulant medications and behaviour therapies are the mainstay of treatment with the nature of the medications requiring accurate diagnosis, judicious use and close monitoring in collaboration with parents, child and school (AAP, 2001). Proper diagnosis of ADHD is difficult, time consuming, and requires information from several sources for accuracy (AAP, 2000; Polaha et al., 2005; Sloan et al., 1999; Wolraich, Lindgren, Stronquist, Milich, Davis, & Watson, 1990). Some physicians will rely on the child's behaviour at an office visit to make a diagnosis which is potentially serious since this can affect the choice of appropriate care, need for referral, treatment choice and monitoring appropriateness and may result in under diagnosis (Sloan et al., 1999; Wolraich et al., 1990). On the other hand, inappropriate labeling of a child with ADHD has a potential to affect quality of life both in social situations and at home and may affect the judgments of both peers and teachers of the child with ADHD (Cornet-Ruiz & Hendricks, 1993). The literature recommends that growth, appetite (Spencer, Biederman, & Wilens, 1998) pulse, blood pressure, and medication side effects need close monitoring. In addition, the child needs close monitoring for desired outcomes and for indications of need for dose increase or reduction (Brown et al., 2005) and the PCP should reconsider the diagnosis if target outcomes are not achieved (AAP, 2001). The recommended frequency of visits is not clearly defined in the literature, but some studies have found improved outcomes with frequent visits especially for the first months after diagnosis and during medication titration (Brown et al., 2005) to monitor a broad range of measures such as the child's response to therapy, family functioning, school performance, and peer and social relations. It is important to monitor for comorbid conditions and early identification of those needing referral to specialized services or

additional therapies (Brown et al., 2005). The guidelines enforce that because learning, socialization and behavioural management are crucial, the school be involved in monitoring the child's condition (AAP, 2001). The medical system needs to be closely involved with the monitoring of these children as well since school professionals are not trained to recognize medication side effects, complications, or the development of co-morbid psychiatric or medical conditions. This reinforces the validity and importance of collaborative management or what the literature refers to as "multimodal care" (Hazelwood et al., 2002) and the involvement of the parent(s). Sloan et al. (1999) reinforce that proper system management maximizes benefits to the child with ADHD when there is coordination between system components including school personnel, physicians, psychologists and parents. This coordinated system involves collaboration and the provision of family-centered care (AAP, 2000; Hazelwood et al., 2002).

When the system fails to provide what the child with ADHD and their family need, both anecdotal reports and the literature reveal that parents advocate for services for their child and subsequently take primary responsibility and become coordinators of care (Thiessen, 2005). The system in the rural area is lacking in school psychologists and other specialty services such as school psychologists who only attend to each school in a division one day per month (D. Anderson, Assistant Superintendent: Student Services Coordinator, Evergreen School Division, personal communication, April, 2005). How well the parent is able to coordinate their child's care depends on their knowledge and resources such as access to a support network or to a PCP for refills of their child's medication. There has been some discussion in the literature about the concept of parents being the case manager of their child with ADHD. The Learning Disabilities Association of Manitoba (LDAM) (Thiessen, 2005) supports the 'parent as case manager' concept as they feel that the parents can play a significant collaborative role in the team within a known 'fragmented system of care'.

### *Primary Care*

With the increased numbers of children with ADHD, this is a disorder managed commonly in the primary care setting out of necessity partly due to a lack of mental health providers (Gardner, Kelleher, Pajer, & Campo, 2004; Wolraich, 2000). There are concerns that the system that exists is fragmented and ineffective to provide quality care to a population such as children with ADHD. Some concerns cited in the literature are that PCPs are not well educated about ADHD (Wolraich, 2000), do not provide care according to current care guidelines despite availability of same (Rushton et al., 2004), do not have the time to provide appropriate care, and are not provided adequate compensation (Gardner, et al., 2004; Kwasman, Tinsley, & Lepper, 1996; Wolraich, 2000). Having mental health support and expertise available to work collaboratively with PCPs improves care (Kwasman et al., 1996; Salman & Kemp, 2002). This demonstrates that in the rural setting, care quality is potentially lacking with the lack of specialized care supports. In the literature, some PCPs have preferred not to provide ADHD care or follow-up services unless specialized services are available (Gardner et al., 2004; Kwasman et al., 1996). This possible lack of PCP participation with ADHD has potential impact on care of these children in the rural setting. In smaller rural northern communities, some parents may prefer to take their children to the local PCP for evaluation and monitoring for convenience and factors such as lack of transportation to other centres. The decision of where parents take their children, and their attitudes about what needs to be done for their child, are impacted by their beliefs, ethnicity, area of residence and factors such as socioeconomic status (Sloan et al., 1999). It makes sense that in the rural settings, local PCP care is ideal since the PCP is in close proximity to the school and may be most available if problems arise.

*Parent Perspectives*

There were no studies found that report parent experiences with the system of care. One study looked at parent characteristics and attitude as having an impact on whether they seek out services for their child (Bussing, Zima, Gary, & Garvan, 2003). Another consisted of examining reports from parents regarding what therapies their physician provided to their child (Wolraich et al., 1990). The other study included parent perspectives about child behaviour problems (not specific to ADHD) and looked at the characteristics of the families that influenced their perspectives (Benzies, Harrison, & Magill-Evans, 2004). Anecdotal reports from various health care providers agree with the premise that few parents have adequate input into their child's care. Parents are central to their child's care as parents are the constant for their child throughout the various sectors in the system. There are many outside pressures affecting parents' views and their decision-making processes for their children. Often, perceived high burden, pressure from the school (usually related to behaviour issues) and their beliefs regarding the origin of the problems influence whether the parents will seek care and what type of care (Bussing et al., 2003). For example, if parents perceive ADHD as a social problem versus a medical problem, they are more likely to seek non-medical help (Bussing et al., 2003; Sloan et al., 1999). On the other hand, worry about stigma could be a motivation for parents to believe that their child's behaviour is physiological rather than psychosocial or environmental. This reinforces the need for parental education and for respecting parent and patient perspectives when designing patient-centered care plans. Cultural background may influence parents' trust of professionals and beliefs about behavioural and mental disorders that will influence their help-seeking behaviours (Bussing et al., 2003).

Influences on the care a child with ADHD receives include such factors as demographics and region in which the child and family lives, attitudes and knowledge of parents and providers,



resources available to the child/family and to their service provider (Sloan et al., 1999) as well as level of collaboration between providers (Halasz & Vance, 2002). Parents of children with ADHD are known to experience high levels of family dysfunction and stress (Kaplan, Crawford, Fisher, & Dewey, 1988) which affects their ability to cope with and understand their child's condition (Pentiliuk, 2002). When such families are residing in a rural setting with limited resources and support, a higher level of stress and family dysfunction will be present in what is most likely a less effective system of care and available resources. Parent stress is a factor affecting care with a known correlation to success of treatment (Chronis et al., 2004). The literature indicates that including the parents throughout the assessment and monitoring of their child (i.e. using a family-centered approach) has been shown to enhance family skills, help them to recognize the strengths and resources they possess, enhance their understanding of the child's condition and contribute to positive family adaptation. Pentiliuk (2002) states that "despite all the theoretical and scientific justification for meaningful parental involvement and collaboration, research suggests this is not universal." Parents' involvement in school activities and communication with the teachers is one of the most important strategies that they use to ensure that their children's' needs are being met in the school and to help them understand their children better and to learn enhanced coping strategies (Pentiliuk, 2002).

There has been both national and international research done on whether parent reports regarding their child with ADHD are accurate. The validity of information from parents plays a significant role if PCPs are relying on parent reports to both diagnose and monitor this condition over time (Biederman et al., 2004). The findings in the literature speak to the necessity of including the parents in both the initial assessment (Pentiliuk, 2002) and the ongoing follow-up assessments of outcomes (Biederman et al., 2004). Parents are intimately enmeshed with their child and will gain insight into understanding their child's struggles and learn about the disorder

and its management when included in the assessment of their children (Pentyliuk, 2002). In the literature, it is common to see parents' reports compared to that of teachers. A study by Saklofske et al. (1999) looked at the consistency of ratings between parents and teachers over a period of four years for children diagnosed with ADHD. They observed the relationships in key areas such as intellectual, cognitive, behavioural and academic measures. The results of the study indicate variability between parent and teacher reports indicating that clinicians need to take into consideration rater variability when using multiple informants for the assessment of ADHD (Saklofske et al., 1999). Several other studies have shown that parent and child reports are credible especially on internalizing disorders and that disruptive behaviour is best analyzed by parent and teacher reports together (Dery, Toupin, Pauze, & Verlaan, 2004).

Most of the research looking at parents of children with ADHD focuses on mothers. Malacrida (2001) states that it is primarily mothers who take on the educational and supportive advocacy for their children in our society. In our current society, women perform more domestic and child-related types of labour than do male parents especially before children reach their teens (Malacrida, 2001). Mothers are additionally burdened with the responsibility for the moral regulation of their children (Malacrida, 2001). With these expectations and pressures from society, mothers may experience hardships when trying to navigate the system in addition to negative views from society when trying to advocate for their children. Most often mothers take their children for health care appointments, get information from the school, and do the majority of the advocating for their children. Despite these trends, it is expected that fathers will be more involved with their children's well-being and with decision-making regarding their children's care than is currently the case. Fathers typically get involved in decision-making and may potentially sabotage the care plan especially when it involves pharmacotherapy (K. Wiebe, Clinical Psychologist, personal communication, July 14, 2005) or the father may choose to leave

the family home in difficult times leaving the mother to deal with them (Benzies et al., 2004).

Both parents have a stake and interest in promoting the best education and social outcomes for their children since those outcomes will have an impact on their family unit as a whole.

### *ADHD in Manitoba*

Incidence of ADHD in Manitoba in one Manitoba study showed an incidence of ADHD in children to be 0.89%. This statistic was surprisingly low given the national and international findings that 1% to 23% of all children have some form of hyperactive-impulsivity symptom (Romano et al., 2002). A reason for the low incidence in the Manitoba study may be that the incidence numbers were derived from physician billing cards that may not be representative of those children seen by non-medical personnel such as psychologists. G. Bobowski, LDAM, personal communication, August, 2005) states that LDAM initially took ADHD as an add-on under their umbrella of services since it did not really fall under any other service in Manitoba. G. Bobowski (2005) recognizes the need to improve services for children with ADHD in Manitoba as they are fragmented. It is difficult to find services specific to ADHD as the condition does not fall into any one specific program. For example, Children's Special Services are available, but only if there is a developmental delay. The Child Development Clinic of Winnipeg focuses primarily on children aged 0-7 years who have developmental issues. This lack of services is a serious issue as most children with ADHD are diagnosed either in grade one or two and therefore beyond 6 years of age. In addition, if they do not have an obvious developmental issue then they are not eligible for services. It was for this reason that an extension clinic in Winnipeg was started that provides service to children after age 6 years and into adolescence (G. Bobowski, LDAM Intake and Workshop Coordinator, personal communication, August, 2005). Children with "only" ADHD do not meet the criteria of "special needs" and it is not until their symptoms are severe that they will fall under children and

adolescent psychiatric services at St. Boniface General Hospital, Health Sciences Centre or Manitoba Adolescent Treatment Centre (MATC). In order for a parent to access services for their child in Winnipeg, they need to contact child and adolescent mental health central intake. This intake service is for children requiring mental health services within the Winnipeg area and connects children with a Child and Adolescent Mental Health Worker (CMHW) and/or psychiatrist as appropriate (J. Sodomsky, Child and Adolescent Intake, personal communication, September, 2005). This access line is meant for the Winnipeg population of children with mental health disorders and anyone that calls from the rural area will be redirected to contact their local child and adolescent mental health worker (J. Sodomsky, Child and Adolescent Intake, personal communication, September, 2005). J. Sodomsky (Child and Adolescent Intake, personal communication, September, 2005) states that rural CMHW can access services and information for their rural clients by calling the line. J. Sodomsky (Child and Adolescent Intake, personal communication, September, 2005) stated that exceptions will be made if a very needed service is not available in their rural setting, but prefers that the person come through their local CMHW system of care.

G. Bobowski (LDAM Intake and Workshop Coordinator, personal communication, August, 2005) agrees that the services for ADHD are fragmented and most times children with ADHD have to be 'shoe-horned' into services by advocates for that child. Social skills and learning issues tend to be the *least* treated, yet are significant problems. For example, behaviour may improve with pharmacologic or behaviour therapies, yet the child may have no friends or know how to read.

Another issue in Manitoba is the long waiting lists for assessments through schools. If parents wish to get assessments done in a timely manner, they have to go through private agencies with a typical cost of \$1200-\$1800 plus the costs of educational tutors if needed.

Recognition of ADHD depends on the attitudes of the teachers and their communication abilities. Most likely, if the child's behaviour is considered "bad" and/or disruptive, then funding might be obtained. The unfortunate part is that once the behaviour improves, the funding often will end. This is not effective since ADHD is a condition requiring continuous intervention to maintain treatment effect (Chronis et al., 2004; Frazier & Merrell, 1997) and benefits from early detection and intervention (Teisl et al., 2001). LDAM notes that upper to middle class families are more likely to recognize symptoms of ADHD, whereas children who are from families of lower socioeconomic class are more likely to have their symptoms attributed to other factors such as parenting problems, abuse or other stereotypical problem relating to socioeconomic class (G. Bobowski, LDAM Intake and Workshop Coordinator, personal communication, August, 2005). Therefore, ADHD may be less recognized in the lower socioeconomic class. Some inequities exist in the system as well, for if you happen to be a foster parent, there is special development and training available plus support groups and associations such as 'New Directions' in the Interlake Region. Otherwise, there are no support groups known for natural parents in the Interlake (G. Bobowski, LDAM Intake and Workshop Coordinator, personal communication, August, 2005).

Some programs are available through LDAM such as provision of resources, advocacy, support and parenting assistance. A common issue identified by LDAM is a lack of awareness of which services are available. G. Bobowski (LDAM Intake and Workshop Coordinator, personal communication, August, 2005) states that this has improved over the last few years as it seems physicians are becoming more aware of LDAM as a resource especially those at Child Development Clinic and the Extension Clinic. Social workers are professionals who commonly refer children to LDAM. The issue in the rural setting is that there are no social workers available unless a provider goes through Child and Family Services (CFS). G. Bobowski

(LDAM Intake and Workshop Coordinator, personal communication, August, 2005) agrees that most parents see any involvement with CFS as a perception of child protection and parents may be afraid of stigma attached to any involvement with CFS. G. Bobowski (LDAM Intake and Workshop Coordinator, personal communication, August, 2005) states that there are little to no phone calls to LDAM from parents in rural areas of Manitoba, with most phone calls from rural Manitoba being rural mental health professionals seeking information.

LDAM describes ADHD as a hidden disability. How will policy and government recognize that changes need to take place? Learning about parents' perceptions and experiences with the system will be a start towards the impetus for change (G. Bobowski, LDAM Intake and Workshop Coordinator, personal communication, August, 2005). Input from parents will contribute to the growing body of knowledge about the best way to monitor needs in these children, find out what they need as a family unit in terms of resources and services, and their recommendations to help to guide effective policy development. Parents are central to their child and need to be empowered and listened to so that their experiences can make a difference for others. There is potential to improve ADHD care by contributing to the field of knowledge through encouraging parents to describe their experiences with the care of their child.

### *Research Questions and Study Purpose*

The questions raised after reviewing the available body of literature were: 1) What do rural parents see as the main care needs for their children with ADHD? 2) What are rural parents' perspectives of the services and resources presently provided to meet the care needs of their children with ADHD? 3) What recommendations do rural parents have about how to improve the system of care for their children with ADHD?

The purpose of this exploratory qualitative research project was to arrive at a beginning understanding of rural parents' experiences with the system of care for their children with

ADHD. The focus of this project was in the rural setting, as there tends to be decreased access to specialized services with an expected heavier reliance on primary care practitioners for care. The type of care children with ADHD receive or whether their needs are met is not known. Parents had an opportunity to voice their experiences and concerns with the system of care through semi-structured interviews. Since the younger age time period has the most impact on long term outcomes such as quality of life (Klassen et al., 2004), and risk for co-morbid conditions in their teen years (Fergusson et al., 2002), parents of elementary age children were chosen for study. An understanding of parental perceptions is required to inform clinical practice with families, as well as policy and program decisions for child and family mental health services (Benzies et al., 2004).

This project explored the assumptions related to the parental perceptions of the care of children with ADHD in the rural area due to the paucity of this type of research in Manitoba. It is assumed that the provision of ADHD care in rural settings is often by rural PCPs with or without consultation to urban specialty health care services and the schools. In addition, it was assumed that parents may not be aware of what is available nor be satisfied with the care their children are receiving as the literature shows that PCPs in other areas consistently not providing care or information to parents according to the clinical practice guidelines. Could it be that parents are not getting enough education or information about ADHD with resulting stress and lack of adequate care for their child? This study explored these assumptions to determine the status of ADHD care in the northern Interlake region of rural Manitoba. It is generally agreed that rural areas such as the Interlake lack in specialty care. Throughout the literature review, no relevant studies were found that included the research technique proposed for this project.

Findings from the literature suggest that development of ways to improve the system of providing care for children with ADHD will be useful. The first step towards this improvement

is to get an understanding of the experiences of families who have children with ADHD. The findings from this project will be submitted to public and professional publications (e.g., newsletters) and scholarly journals in the hope that the findings will contribute to the development of awareness amongst educators and health care providers and to encourage and demonstrate the need for increased collaborative efforts.



## Chapter Two: Methodology

The purpose of this chapter is to describe the methodology used for this study and its rationale. This discussion will include the site for study, sample, and data collection techniques. The methods of data analysis and management are discussed along with ethical issues taken into consideration.

The design chosen for this study was exploratory in nature to elicit thoughts and feelings to obtain descriptive data about parents' experiences with the system of care for their children with ADHD. The interview questions had an open-ended design to encourage expression of experiences and open discussion of issues and recommendations.

### *Site and Sample Selection*

This study employed a convenience sampling technique. A sample of seven rural parents was obtained consisting of the first seven respondents who met the inclusion criteria. Participants met the inclusion criteria if their child previously received the diagnosis of ADHD, they resided in the northern Interlake and spoke English. Participants were included regardless of the treatment status of their child with ADHD. The study sample consisted of mothers, one grandmother (she was the primary caregiver therefore was included in the study) and one father. Six out of seven participants were Caucasian and one was of aboriginal descent. The sample of children with ADHD varied from ages 7 to 12 years. The parents (or guardian) had experienced the rural system of care as they went through the elementary school system in the rural Interlake setting. All of the participants' children were currently attending elementary school in the rural Interlake setting and were currently receiving some form of treatment. Each parent reported that their child had been diagnosed by either psychology or psychiatry with various methods of assessment reported.

The study sample was obtained by placing posters in communities, grocery stores, schools, local health centers, and convenience stores. An advertisement (Appendix A) calling for participants was placed in the local newspaper over a two-week period in the area that reaches the northern Interlake extending from the west side from St. Laurent up to Gypsumville then across to the east of the Interlake from Matheson Island then south to Winnipeg Beach. Gaining access to the study sample was limited to the amount of parent interest in participating in the project. Participation was strictly voluntary and written consent (Appendix B) was obtained prior to the interviews. Interviews took place primarily in participants' place of residence.

#### *Data Collection*

Qualitative data from semi-structured interviews were recorded then transcribed. The interviews used a semi-structured approach and the interviews varied from 60-120 minutes in length. The interview consisted of questions to parents about their experience with the system of ADHD care after their child received the diagnosis of ADHD. Included were questions regarding their child's care needs, services, resources provided and utilized, what they like best and least about how their child's needs were being met and their recommendations for improving the system of care (Appendix C). Data collection took place in such a way to minimize inconvenience and promote access and privacy to participants. Individual parent interviews took place in a setting of their choice, primarily their own homes, at a time convenient to them. Credibility of the data was encouraged by creating an atmosphere of trust, sensitivity and authenticity during the interviews so that the parents felt comfortable relating their experiences in an open, honest manner (Benzies et al., 2004).

#### *Data Analysis*

Each interview was transcribed verbatim into paper format. The interview data was organized and summarized according to each research question. This process helps the researcher to

immerse themselves in the data and to be more aware of the 'life world' of the respondent (Burnard, 1991). Original wording from the interviews are included in the analysis since as Burnard (1991) reinforces, merely to cut out strings of words devoid of context is to risk altering the meaning of what was said by the participant. The writing up of the results took place using a comparison and contrast from both literature and anecdotal reports. The findings section of the project includes references to literature that make it more readable and practical (Bernard, 1991).

### *Ethical Considerations*

The potential for parents to experience risk and harm during the course of the study was considered to be minimal. However, because of the potential for some parents to experience increased stress in relation to recounting negative experiences with the care of their child with ADHD, local mental health services were made aware of this project. A list of appropriate services and contact information for those services was offered to participants if the researcher, a Registered Nurse, determines a need for services, (e.g., respondent appears distraught). No need for mental health services was identified for any participants for the duration of this project. This project (non-therapeutic) has no direct benefits to participants. However, parents expressed appreciation to be able to share their experiences especially since most have not had the opportunity to discuss their experiences. This project received approval by the Human Subjects Research Ethics Board at the University of Manitoba.

### *Managing and Recording Data*

Hard copies of completed questionnaires (study data) were maintained in a locked file cabinet at the researcher's home to be accessed only by the researcher. The tapes will be destroyed once the full analysis and the project is completed. Only the researcher and members of the practicum committee have access to the data. No names are used in the writing up of the data.

*Dissemination to Participants*

The consent form contained an optional section for participants interested in obtaining a written report of results to document their name and contact information. Those that have identified that they would like to receive a report will get one through electronic or paper mail depending on their preference. Participants were encouraged to give feedback on the report.

*Summary*

A qualitative exploratory study was used to elicit experiences and perceptions of parents regarding the rural system of care for their children with ADHD. Parents' perspectives were summarized and put into a format with direct quotations to bring full meaning to the discussion. The findings from the study are presented in the next chapter.

### Chapter Three: Results

The interviewing process began with the intent of revealing parent perspectives of the needs and resources required of their children with ADHD. The core of the interview revealed what they liked most and least about their experiences with the system followed by their recommendations on how to improve the system of care. Each part of the interview is reported in sections, with the findings supported in detail by quotations from participants. This process of discovery was challenging and enlightening as thoughts and experiences unfolded bringing to life the experiences of parents.

#### *What Were the Needs of your Child at the Time of Diagnosis?*

This question proved to be difficult for the interviewees to interpret leaving the interviewer with data not necessarily expected. The responses the interviewer expected would have included responses such as specific school- and home-based needs. When asked to discuss the needs of their child at diagnosis, all parents primarily used this as an opportunity to identify the problems with their child that led to the diagnosis. In recognizing that the above question was not answered as anticipated, the findings proved to be very interesting nonetheless. As well, the responses indicate where the parents' foci lie; Why is their child so difficult to manage and why are the resources that are available to improve the situation falling short?

In terms of what led them to believe there was a problem with their child, all parents identified that their child exhibited impulsive behaviours and at times described erratic, violent or aggressive behaviours. They described their child as hyperactive, unable to focus and cited sibling rivalry as a common problem with their child needing close supervision and repetitive reminders about basic tasks on a day-to-day basis. They described their child as showing different signs from other children their age "he just acts out of the blue and there was no

explanation for it...just out of control.” They describe their child as difficult to parent yet “...but later on, once we got the diagnosis I realized he really couldn’t help it, he didn’t know that he was doing things...he had no impulse control at all.”

All parents described their child as very bright. In fact, in those who had IQ testing, their children were in the 98<sup>th</sup> percentile, “which you would not think they would have with ADHD and no impulse control.” “...If they were that smart, you would think they could control it...but that’s just it, they can’t.” The majority of parents described their child as falling behind in school because they could not sit still or focus on their work and the teachers were annoyed. Parents describe social challenges such as inappropriate behaviours with other children, excessive emotional outbursts with losing in sports and anxieties associated with planned activities. Several parents describe their child as having anxiety levels beyond normal when faced with a task or event and not understanding why. “We never really thought of ADHD as the possible culprit.”

Services accessed soon after diagnosis described by the parents were primarily those accessed to get a diagnosis for their child or to find out why their child’s behaviour was so seemingly abnormal. Services accessed included Child Guidance Clinic (while one parent resided in Winnipeg), which was lost when they moved rurally. Local Community Mental Health Workers (CMHW) leading to use of child and adolescent psychiatry services were utilized for those parents aware of the service in their community. Most parents discussed resources not only as part of initial diagnosis, but also as part of initial management of the condition. Other services mentioned that were utilized included psychology, psychiatry, (Manitoba Adolescent Treatment Center (MATC), and CMHW.

In this question parents described the classic challenges associated with ADHD. These are sibling rivalry and parenting challenges, behaviour issues, and issues with school performance.

The parents expressed frustration with the system initially, because of time it took to get any help and to figure out what was going on with their child. “We knew he needed more than just regular play in school and stuff....and ...it took so long to get any kind of help.” This kind of information gives a sense of the frustration that parents experience when having children with ADHD.

*What Services and Resources did you Access for your Child?*

An interesting observation occurred after asking the above question. It became quite clear that parents had very little knowledge of the services and resources available to them. This led many parents to be proactive and work with a teacher, educational assistant and other professionals who were kind enough to “help.” However, most parents, leaving them very frustrated, believing they had to face this problem on their own, did not know of the resources that specialize in ADHD. Below are actual quotes and experiences reflecting this.

Much frustration was expressed on the part of the participants related to difficulties associated with finding help when needed. Several participants expressed frustration that there were no services at all for them in the Interlake. “I screamed for help and nobody would help me.” “I got no services as I was told he was not bad enough.” “It seems no one will help until something really bad happens – until my son injured my daughter and she was sent to the hospital...then family services got involved as they thought we may have hurt her...after this we finally got some respite as they realized he was a handful.”

All parents expressed that their school seemed to have nothing to offer their children and one parent did not feel that academic help was necessary. “In school, we were told that his needs...or his learning disability wasn’t severe enough to qualify for supports for education.” “...In fact, if he received any assistance, it was out of the kindness of the Educational Assistant (EA), not that the service was specifically for him.” Some parents had a supportive guidance

counselor in the school who was willing to advocate on their behalf... "Our guidance counselor was great, she really looked into what the needs were and took it upon herself to contact St. Boniface...it really took a weight off my shoulders to know that someone was willing to help us and believe in what I was saying." The majority did not have assistance from a guidance counselor or were even sure that there was one available. "Our guidance counselors are the vice principal and principal, and none of the kids like them...it should be someone from the outside doing that job" or "We don't even have one as far as I know, or I never see them."

The parents who described a good experience in the school clearly had a good working relationship and good communication with the classroom teacher. "We lucked out with our grade 3 and grade 4 teacher...he was great, he asks questions, he lets me know if the medications are wearing thin by the end of the day and keeps me posted on his behaviour." Alternatively, they had a good relationship with a particular individual in the school who was willing to advocate for their child such as a particular teacher or even the receptionist... "The secretary helped him, every lunch hour he would spend lunch with her and help her and she "fell in love" with him...for two years she did that, when no one else would help me." "The teacher took him under his wing this year."

Most participants saw their GP for medication refills locally or in Winnipeg, "We only see a GP for refills and don't see an ADHD doctor at all!" They expressed having a hard time finding services appropriate for their child in their communities or within reasonable distance. "...they told me that I don't have access to the CGC anymore now that I am outside the perimeter"....or services they try to get turn them away... "They told us that "No, we don't deal with ADHD...we are child psychology...we deal with kids with serious psychology problems and she would not fit into that category." Some parents had regular contact with psychiatry or psychology every 3-4 months at distant sites like Selkirk, Stonewall or Winnipeg, but felt it



would be better to have more services especially services close by and easily accessible. “Not everybody has access to transportation in our community, so how will they get help?”

Parents stated that they got most of their self-help or information about ADHD for themselves from either the library or internet. Most find that they do not get much information from anyone about what to do or where to go if there is a problem. “To this day, we still don’t know where to go and no one can tell us anything.”

Only one parent interviewed had even heard about LDAM, none were referred to LDAM or knew that that organization provides support and information to children with ADHD and to their families. LDAM (G. Bobowki, LDAM Intake and Workshop coordinator, personal communication, Sept., 2005) stated that she is not aware of any calls from rural parents.

The above findings indicate a lack of communication between the families and resources available. This suggests that the rural people face special challenges in finding the help they need.

#### *What are the Current Needs of your Child?*

This question continued to reveal the parents’ frustration. Despite some success with pharmacologic treatments and counseling services, they were still unable to pinpoint their child’s true needs. Within this question, the interviewer used prompts requesting that the parents comment on needs such as mental health, specialized ADHD services, school and home which helped to direct them to answer this question more systematically and to get the required information.

Parents described their child as needing mental health services to help with regulating medications and for counseling. All children in this study were taking stimulant therapy and a small number were taking antidepressants and antipsychotics regularly. Local CMHW use was variable with some accessing them bi-weekly for counseling and some seeing only to gain access

to psychiatry when needed. Parents state that their local GPs listen to their frustrations, do not seem to know much about this condition, make sure that their children are medically OK and arrange lab tests as needed. Most state their local GPs or distant pediatricians refill the medications under the direction of psychology or psychiatric recommendations. "The doctor refills the medication, but it is the psychiatrist who makes the recommendation for changing it and the doctor enforces his recommendations."

Most parents have access to some form of psychology or psychiatric services. All those who access these services are driving from 40 minutes to 2 hours to access them. None of these services were mentioned as available in their own communities. Some children are under the care of the local CMHW and the type of service varies by community, depending on the method used by the particular worker. Some CMHWs do regular onsite visits to the schools and some require the children to come to their office for appointments. All parents who want their child to see the Interlake child psychiatrist in Stonewall must be involved with their local CMHW. When discussing frequency of psychiatric services, parents said, "It is frustrating as it is so far between visits, it takes so long to get things started"... "this hanging by a thread leaves the school in limbo too because we don't know anything." Parents expressed frustration regarding lack of information. "That's another thing...no information for the parents through the psychiatrist...then when I ask to get a copy of his findings, he tells me we don't get it, that we have to get it from the pediatrician...like I mean...this is my child!" When dealing with the mental health system, "it seems like I am restricted to what I can say and what I can't say...it is frustrating!"

All parents expressed a need for more help for their child in school. The type of help varied between self-help, assertiveness, and social training in addition to academic assistance. Most children have no EA services and the ones who have part time EA services feel that there is a

need for full-time EA services. The needs expressed by parents include the need for constant reminders and direction in the classroom, counseling for social skills, self-help and assertiveness against bullying. One parent expressed that her child would benefit from self-awareness counseling..."I guess in that area, it would be nice for her to have someone to talk to about ADHD and what it means to her"... "She doesn't really understand how she is different from other kids...if she had access to that, it would be great." Most parents expressed a big change in school performance once their child was given stimulant therapy... "She does well in school as long as she is on her Ritalin." "Once he started on Ritalin, he went to the top of his class." Several parents expressed that their child needed to have somewhere to go within the school system where they would not feel threatened. For example, parents expressed that their child was labeled by educators and has no one to talk to "they deny that they label him, but they do." "The counselors in our school call him in to teach him not to behave incorrectly...it is disciplinary... so he is more threatened by it than anything." "they don't teach him how to control it, it is punishment for misbehaving"

Parents not only described issues at school, but also at home. "He needs encouragement to start, focus and complete homework...the homework can be a real source of anxiety and frustration for him. He shows this by yelling, screaming, swearing and avoiding that area as much as possible". ... "any distraction will pull him away from the task at hand." Parents said that they have to repeat things repeatedly to their child and often there was anger management problems and sibling rivalry, which make home life more challenging. Two families were given some respite care after pleading for it or after serious events have happened in their families to make Family Services take notice. Parents have tried to advocate for their child to "prevent something bad from happening before it happens," but have described not being able to get that for their child. Participants who have received respite services have felt it very helpful and that

“it is something special for him...it’s like his own special time and it makes him feel good” and felt it was useful as long as the respite worker was a good match for their child. It appears when a need was identified; access and awareness of resources remained to be lost in the communication process between parents and the multidisciplinary involved.

*What did you Like Most About Your Experience with the System?*

Parents expressed satisfaction with mental health professionals making recommendations to the school. “I want to make sure that the school is held accountable that...you know...for these recommendations...that they won’t just put them on the shelf like before.” It was common to hear satisfaction described with evidence of teamwork in the care of their children. “I like the fact that everyone is starting to come together...just work together...so that my son can continue his education”.

Many parents were grateful to their local GP and pediatrician to give them support and be there to refill their medications as they have expressed it is difficult to get in to see their psychologist or psychiatrist. Parents spoke of being pleased that there now seems to be a beginning awareness in the public about ADHD as a condition that needs identification and treatment. They expressed that public recognition of the disorder will promote their communities to advocate for more help for these children.

Some parents expressed satisfaction that the school is trying their best to help and be supportive of them. “They are trying to be helpful, but not sure how much they know about ADHD.” Most parents did not feel that the school was very helpful and had a hard time finding anything positive to say... “I don’t like them at all; I don’t know what to say here.” “His teachers have been good, really approachable, but the system itself...well, there hasn’t been a lot there, or any contact person” and “there is not much good I can say about the system.”

Usually parents struggled with the question about what things they liked most about how the system meets their children's needs, and mostly negative things came out in the discussion.

"Once you get them on your side, so to speak, they are helpful, but it takes so much work and so much energy to get them on your side in the first place". Despite the frustrations, parents indicate that the professionals are making efforts. However, the system is very fragmented and this leaves even the most well-intentioned actions unproductive.

*What did You Like Least About Your Experience with the System?*

There were numerous responses to the question asking about what they did not like about the system of care. Parents were eager to discuss their difficulties in the system of care in general.

A primary theme that emerged was that specialists made recommendations, yet the school did not put them into place. "No one is being accountable to what their jobs are...because my son can't read!"..."I sent him to school to learn to read and write and it is not being done...that's a big frustration and kind of makes me angry that they are not doing their part." "Nothing happens unless I initiate it." The parents do not see that the resource teachers are involved in helping out unless they are doing paperwork to try to get funding...yet "once they get the funding, they seem laid back when they get it." The worst thing is "the waiting till we had a crisis till anything was done...I have been fighting for help since school started...but...as he gets older the problems get bigger." All parents interviewed felt that the school system was not educated enough to know what was going on with their children and did not have the understanding about what was needed. "They need more insight into these kids." "Everyone in the school system from the top down needs more education"... "Ya, they have their degrees, but not knowledge to deal with this...they are set in their old ways and just don't know how to deal with these kids...bus-drivers should be educated as well...they have kids on the bus from Kindergarten age all the way to grade 12 on their bus and need to know how to deal with these kids too." "Some teachers don't

know how to handle the kids properly; they lose their temper and yell a lot...maybe they need more training?"..."I observed kids climbing up the bookshelf then they have them paged to the office because they can't control them...the numbers of kids in classroom is too large"...

"ADHD children cannot function in an environment without proper structure." Parents suggest more training for educators with smaller classrooms giving them better control and organization in the classroom with a better environment for the children with ADHD which will then improve their functioning.

Some parents are confused about the processes that take place in the system and about the lines of communication that are supposed to take place. "They keep shuffling around like it is this person's responsibility...or that person's responsibility...no one is accepting responsibility...like through mental health I could not see a psychiatrist because this service is through the special services office? It is through special services office that is supposed to arrange for assessments. ..." "I never know if she is on enough Ritalin or not enough Ritalin...I have nowhere to take her for this and I don't know what to do and I don't know if the guidance counselor is trained or not." "It took till grade 2 to get anything going...it took sooo long." Parents expressed frustration on several occasions in the interviews about the whole diagnostic and treatment process. "Because we chose to use the public system, the diagnosis and for that matter the treatment program took over one year to happen. I wonder how much pain and struggle occurred unnecessarily...So, in hindsight, if there is something that makes a parent unhappy, it is the long drawn out process involved..." The general concern expressed was the length of time having to wait for services.

When parents feel that they are in a difficult or even a crisis situation, they expressed frustration about where to go to get help. "There should be someone we can call for help"..."if you don't live inside the perimeter, you can't access the child crisis team, they won't come

outside the perimeter”. ”When we had a major breakdown, my doctor tried for 1 ½ weeks to get us some help...finally...I took the paperwork in hand and had to show up at Children’s emergency...to get any results! Even the local mental health worker couldn’t help me.” Another parent said, “It is concerning that, if something happened, who do we turn to?”

Parents were generally dissatisfied with their experiences with the system of care. A frustration with a lack of trained providers especially in the school setting was a main theme identified with this question. Parents report lack of knowledge about available resources to help them in their time of need including mental health and crisis services.

*What are Your Recommendations to Improve the System of Care?*

Parents had several interesting recommendations for how to improve the system of care for their child with ADHD. Parents identified that awareness by the public and within the school system about ADHD and its significance is a big priority. Then, if the community knows that it is such a problem, they can advocate for the children in their communities to get some help. The community should have things to offer in our community so you know that someone is here that can help us instead of traveling all over the place”... “More access in our town would be a highlight and something that is really needed. There is a lot of people who need help here.” Once the town knows that there is such a need for it, and then the needs can be met here, not everywhere else outside of where we live.” ”ADHD is a real problem and it needs to be addressed!”

Most parents emphasized that it is important for everyone to work together. “Things need to be hashed out and dealt with!”...”Everybody needs to start working together and not against each other!” One parent made a suggestion: “A more integrated system would speed up the care needed immensely. I suggest this could be accomplished by developing a standard procedure that would involve all disciplines.”

Repeatedly in the interviews, problems with the school were revealed related to funding, accountability and lack of training for the teachers and other para-professionals that work with the children. One parent stated "I was informed that the school received funding for a lot of these services...it's like the school doesn't want to know that the child has a problem...because then they might have to spend that money on that child and...not on something else...so you know...they need to get their act together..."

Another parent identified the need for the school system to be educated in early identification as this is a key environment in which children spend a great deal of time. "I feel the school system should be properly trained to identify possible ADHD in students. The benefits to the child, families and educational system are obvious. Early detection could be caught at the school as it is where the child spends hours of each day in an environment that truly provides a testing ground unparalleled to all others." "The school should be involved in early detection through a few of the early years, as I believe ADHD would become evident during that time, then the appropriate diagnostics and treatment can be started"... "if we could catch this before it gathers speed, the important developing years wouldn't be jeopardized. As well, the benefits to society would be endless. It is no secret that ADHD can lead to troubled teenage years, poor jobs, and poor self esteem, all of which are areas we would like to prevent." This parent's perspective is certainly in line with the literature, which reports on the significant impact of early detection and intervention with children with ADHD (Sloan et al., 2005; Teisl et al., 2001). These findings in the literature show impairment in the development of the child if untreated and report that the school should be involved in this process (Brown et al., 2005).

Parents are sensitive to the fact that it is not just their child who has problems, but that there are plenty of other children in their community who need help as well and who are not getting it or their parents can not afford to drive them to get care. This emphasizes that whatever services



can be provided in the school will be of benefit for those smaller towns as the parents and children are able to access those. Parents have said that it is a relief to have someone in the system who believes in you and is willing to help. The parents should be directly involved with the school in a respectful way as part of the team as they “know their child best.” Recognition of the parent as an expert will go far to give them the respect they need to be strong and keep them empowered as advocate for their child. Teacher attitude and willingness to help is evident to have an impact on parents and determines parents’ perceptions of the school as a helping environment.

This chapter reviewed the results of the research project. The data is organized according to the questions asked of parents in the interview process. The areas discussed include needs of children with ADHD identified at time of diagnosis, services and resources accessed to meet these needs. The nature of parent experiences and parent recommendations to improve the system of care for children with ADHD has been explored. The discussion of these results will follow in Chapter Four.

## Chapter Four: Discussion

The purpose of this chapter is to discuss the results of the study and how they compare to the literature. Recommendations for change and future research are made. Parents have identified some key areas in ADHD care that need to be addressed. These include early detection and recognition, feelings about parents as coordinators of care, school issues, discussion about the importance of collaboration, and issues related to access to care.

### *ADHD Recognition*

In interviews, all parents expressed concern about their experiences with the system of care in rural Manitoba and have voiced the necessity to be a strong advocate for their children otherwise they would not have received any help. Thiessen (2005) agrees that parents tend to take primary responsibility and work as coordinators of their children's care. This does not work for all parents unfortunately especially when their pleas are ignored or if they do not feel they have enough knowledge to pursue the care or to find the right service that their child needs. The findings reinforce ADHD as a disorder that falls through the cracks. No one entity is willing to take ownership of this problem. Parents report that psychology and psychiatry in their region do not see ADHD as their responsibility; the school does not recognize ADHD as a problem or a learning disability requiring intervention. Two parents reported positive experiences in an urban center when they first received the diagnosis when the psychologist / Child Guidance Clinic were in the school and readily available to provide the support and assistance needed. This suggests that close proximity and direct involvement by mental health professionals in the school system promotes a better experience, better access and care and more satisfaction reported from families. The literature reports that having mental health services in close proximity and available to work with PCP improves care (Kwasman et al., 1996; Salman & Kemp, 2002).

Close proximity means that there is a higher chance of true collaborative efforts between the various providers in the system. When educators label parents as needy and are not willing to listen and when they label these children as “problem children,” how are parents supposed to be successful in getting their child help in such a system? Attitudes of educators and others in the system will influence the public degree of acceptance as well, especially if they are receiving incorrect impressions or information about these children. Members of the team have to come to a common understanding about the problem and work together towards common solutions. This is expected to increase parent satisfaction, quality of care for these children and a more smoothly run system of care.

#### *Parent as Coordinator of Care*

The concept of parents as coordinators of care has been discussed briefly in the literature (Thiessen, 2005). Given that the care of children with ADHD is complex and difficult, the question may be raised as to whether parents should be primary coordinators of care. Parents are emotionally connected with their children and may not be objective in the assessment, decision-making and evaluating outcomes. Parents may not be aware how or when to make a decision, or to seek a service if they do not have the knowledge and are in a stressful situation. For example, will parents understand the meaning and application of checklist data? How do parents go about setting goals and monitoring their child if they do not have the knowledge or support of a team to do that? This is where teamwork and collaboration comes in to capitalize on each team members' strengths to provide a component of the child and family's care. During the interviews, some parents verbalized that they needed specialists or doctors' care to decide when medication doses need to be increased and reduced. Yet, another parent in the same situation may be confident to manage his or her child's medication and have a greater understanding.

### *Early Detection*

Early detection of children with ADHD and early intervention seems to make sense when this is heard from parents and the benefits of early intervention are known from the literature. There are not only benefits in early intervention in ADHD, but also in early treatment of any identified learning disabilities and other academic problems. The staggering incidence of co-morbid learning disabilities for up to 70% of children with ADHD (Marshall et al., 1997; Mayes et al., 2000; Molina & Pelham, 2001) should certainly lead parents and professionals to take notice of all children with learning disabilities and have them assessed for ADHD. This early intervention can potentially prevent long term effects associated with low self esteem such as low academic success, poor peer relations, other co-morbid psychiatric problems, trouble with the law and substance abuse (Crist, 1999; Ferguson et al., 2002; Molina & Pelham, 2001; Snyder et al., 2004).

### *School Issues*

All parents mentioned in their discussions about school, that educators need to be more knowledgeable about what is happening in the mind of a child with ADHD. Parents indicated that this would help them to understand these children and be better equipped to help them in the end. Thus far, ADHD is not recognized as a special needs diagnosis in our school systems in Manitoba unless there is serious behavioural/psychological/emotional or developmental issues (D. Anderson, Assistant Superintendent: Student Services Coordinator, Evergreen School Division, personal communication, April, 2005). This lack of recognition misses out on those children who have ADHD, especially those of the non-hyperactive type as they typically do not have behaviour issues, and can easily be missed. It was mentioned frequently throughout interviews that there needs to be more in-school support network for both the children and their families with connections to the outside for support and with ongoing psychological and

psychiatric care for these children.

### *Collaboration*

Effective treatment must include working directly with parents. This collaboration is supported by literature (Pelham et al., 1998; Multimodal (MTA), 1999). Multimodal care as discussed by Hazelwood et al. (2002) would give the maximum benefits to the child (Sloan et al., 1999). This is what family centered care is all about. Each situation with a child with ADHD must be considered individually. Variances exist from family to family, which reinforces the need for individualized plans of care (Frazier & Merrell, 1997). So, it makes sense that if you have no teamwork, there will be more variances, more confusion, more fragmentation, and therefore less positive outcomes.

### *Access to Resources*

A major concern identified with the rural system is the lack of crisis services. Several parents voiced concerns about this and one had a direct experience with being in a crisis and having nobody to turn to and no one in the system who could be of help to them. The mental health crisis teams in the Interlake Region will respond only to calls for individuals age 15 years and over.

LDAM is a primary support and information resource for professionals, families and children with ADHD themselves. Yet, only one of the parents interviewed had even heard of this association. Many had heard of LDAM, but thought it was only for learning disabilities. This would explain why LDAM stated they are not receiving calls from parents in the rural area (G. Bobowski, LDAM Intake and Workshop Coordinator, personal communication, 2005). Perhaps the association should have something about its association with ADHD clearer in its title, since this is unclear.

Another primary issue expressed by parents is the unreasonable length of time required to get in to see specialty services either for crisis, for general information and diagnosis when the child is initially identified as having some issues or concerns. Most parents feel that their GPs do not have enough knowledge to care for their child's mental health. They perceive the GP as being there to follow the specialist's advice, listen to their frustrations, prescribe the medication as instructed and monitor their child's general medical health. One participant identified their local GP as a primary caregiver to their child who provided monthly counseling as well as medication refills. It depends on the skill-set of the particular GP whether they are more or less involved in the child's mental health care. It is not really known how often a child with ADHD should be monitored. The ideal frequency of monitoring really is unknown but some research has shown benefits of monthly visits (Brown et al., 2005).

On-site access to mental health and specialized services was clearly associated with parent perception of a good quality of care for their child. This was evidenced by a very positive parental response to the availability of Child Guidance professional staff at their school in Winnipeg. They had access to information, support and care right onsite in the school and felt that their child had good quality of care within that type of system. This close proximity of mental health services is supported by the literature as having a positive impact on quality of care and patient satisfaction.

It has been demonstrated in the literature that a common contributor to non-diagnosis or poor management of ADHD is the lack of appropriate health care professionals (Manitoba Health Research Council, 2001; Miller, Lalonde, McGrail, & Armstrong, 2001). It was found in the interviews that these challenges are more prominent in rural settings such as those in the Interlake where there is a lack of specialized services such as psychology, psychiatry, speech therapy and specialized education. It is known that care for children with ADHD is hampered

by what is “missing” from the system such as parent support, education, training and social skills groups similar to as discussed by Hazelwood et al.(2002). The parents and their children with ADHD in the rural locations report having to commute to urban centres to access needed services. The ability to access these specialized services is influenced by families’ socioeconomic status and access to means of transportation both as reported by participants and by their impression of others of need in their communities.

### Conclusion

Overall, parents are dissatisfied with their experiences in the rural system of care in the northern Interlake Region. Parents of children with ADHD are an aggregate who require support, information and to be heard when it comes to the wellbeing of their children. There are clear needs identified by parents for improvement of communication between care providers and between the system and parents in general. Parents feel that they know their children best and should be included in the planning for care and services. The perception of at least “willingness to listen and help” on behalf of medical providers and the school system were a positive focus of parents throughout the interviews.

Recognition of ADHD as a “real problem” requiring intervention by the school system and by the general public in their local communities was recognized as a problem. Lack of access to appropriate care and crisis services in rural communities was identified as a serious issue in all areas of the Northern Interlake. Parents feel that the school system needs to be more educated to be able to provide appropriate health care services for their child. Some parents mentioned that some of the newer teachers starting their careers tend to have more knowledge about ADHD as a condition than the teachers who were educated some years ago. This reflects a change in how teachers are being educated in the system and it is expected they will bring their knowledge and expertise to smaller communities promoting better recognition and care both for children with

this disorder as well as their families.

Recommendations for further research in this area include taking a closer look at education leaders and teacher's perspectives of ADHD. An exploration of the current system of care looking at the medical and mental health systems and their procedures for providing care to these children will clarify some of the confusion and questions parents have. This will lead researchers to facilitate communication between the various sectors and to help them realize that better communication needs to take place with parents of these children to assure that their efforts and treatments will be effective. This may lead to self-evaluation on behalf of the various systems of care and be the impetus for change within the system.

This was a study of seven parents which revealed the experiences of parents who have children with ADHD in the system of care. Findings indicate that the rural area is lacking in resources and parents find themselves functioning as advocates for their child in a fragmented system. A general dissatisfaction with the rural system was noted in the study. Parents indicated that ADHD is a condition that requires recognition and intervention by both the system and communities in which they reside. Parents indicated that once their child was labelled as a 'problem,' it was very difficult for the child and family to find adequate supports especially within the school system.

A beginning understanding of parent experiences was achieved by this study, which gave an awareness of the needs of this population which are worthy of further study. Future research should focus on exploring the incidence of ADHD in the Manitoba system, as well as comparing incidence to the amount of resources available to treat the condition. Further research should look at the perspectives of other sectors involved in ADHD care such as school, mental health and the medical system and utilize their suggestions when planning for change or improvements.



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## Appendix A

**INVITATION TO PARTICIPATE IN A RESEARCH PROJECT ON  
Attention Deficit/Hyperactivity Disorder (ADHD)**

**Research Project Title:** Rural Services for Children with ADHD: The Experiences of Parents

**Conducted By:** This project is being conducted by Diane Gudmundson, RN, BN as part of the course requirements for the Master of Nursing program at the University of Manitoba. Project supervisor is Dr. Christine Ateah, Faculty of Nursing, University of Manitoba.

- **WHAT THIS PROJECT IS ABOUT:** The purpose of the project is to learn about the type of care provided to children with ADHD who live in rural settings.
- **WHO CAN TAKE PART IN THIS PROJECT:**  
Parents who have a child with ADHD between the ages of 5 and 12 years who:
  - Reside in the Interlake Region
  - Are English-speaking
  - Are interested in participating in this project
- **WHAT IS REQUIRED OF PARENTS WHO TAKE PART IN THE PROJECT:** Parents will be interviewed about their views on the care that their child is receiving for ADHD. The interview will take approximately 40 minutes. Interviews will be scheduled at a time and place most convenient to parents. All information received will be anonymous and no names will be used.
- **WHO TO CALL IF INTERESTED:** Interested parents may contact Diane Gudmundson, Graduate Nursing Student (Faculty of Nursing, University of Manitoba) at:





## Appendix B

UNIVERSITY  
OF MANITOBA

Consent Form

**Project title:** Rural Services for Children with ADHD: The Experiences of Parents

Project Leader: Diane Gudmundson RN BN Phone: (204) 642-4752

Committee chair: Dr. Christine Ateah, Associate Professor, Faculty of Nursing

Phone: (204) 474-6220

Internal member: Dr. Roberta Woodgate, Assistant Professor, Faculty of Nursing

External member: Dr. Ken Weibe, PhD, C. Psych

**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 involve. 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.**

This project is part of the practicum requirement as a graduate student in the Faculty of Nursing, Nurse Practitioner major at the University of Manitoba. The purpose of this research project is to arrive at a beginning understanding of rural parents' experiences with the system of care for their children with ADHD. In addressing the purpose the following three questions are asked:

- 1) What do rural parents see are the main care needs for their children with ADHD?
- 2) What are rural parents' perspectives of the services and resources presently being provided to meet the care needs of their children with ADHD?
- 3) What recommendations do rural parents have about how to improve the system of care for their children with ADHD?

Participation consists of a personal interview at your convenience. The interview will be one time only and will take approximately 40 minutes to complete. You will be given the option to participate in future research regarding ADHD by providing your contact information at the end of the consent form.

There is not expected to be any risks to you in participating in this study. However, should discussing your experiences cause you distress, you will be given a list of service providers that may be of assistance to you. Your personal name, location or other personal identifying information will not be used in the analysis or reporting of data. All identifying information will be kept strictly confidential and will be seen only by the student and committee members. This information will be kept locked and only the student and committee members will have access to it. The information will be destroyed at the end of the study.

When people participate in a study, they often have an interest in seeing the end result and reports once completed. Study results can be provided through email or Canada post for those who give their contact information at the end of this form. There will be no form of remuneration for your participation in this study. The cost of mailing final reports to participants will be the responsibility of the student.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Student: Diane Gudmundson RN BN  
Gimli, Manitoba. R0C 1B0

Project Supervisor: Dr. Christine Ateah  
Associate Professor, Faculty of Nursing  
University of Manitoba  
(204) 474-6220  
Email: [christine\\_ateah@umanitoba.ca](mailto:christine_ateah@umanitoba.ca)

This research has been approved by the Human subject research ethics committee at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

---

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

---

Researcher and/or Delegate's Signature \_\_\_\_\_ Date \_\_\_\_\_

### **OPTIONAL SECTION**

1. I am interested in receiving a report of the results of this study?

- a) Yes
- b) No

If yes, please indicate your preferred method:

- (a) email
- (b) Canada Post

2. I am interested in being involved with future research projects in the area of ADHD?

- a) Yes
- b) No

If you answered yes to 1 or 2 above, please provide your:

Name \_\_\_\_\_ Title \_\_\_\_\_  
Address \_\_\_\_\_ Postal code \_\_\_\_\_  
Phone \_\_\_\_\_ Email \_\_\_\_\_

## Appendix C

Interview questionsDemographics and Background Data

Parent involved in interview: _____	Parent age _____ Parent Sex _____ Child age _____ Child Sex _____
Co-morbid conditions: _____	Rural municipal location of residence: _____
Ethnic background: _____	Child diagnosed by (type of professional): _____

1. What care needs did your child have when he/she was diagnosed with ADHD?
2. What services and resources were provided to your child when he/she was diagnosed with ADHD?
3. What care needs does your child have presently?
4. What services and resources is your child presently receiving?
5. What do you like best about how your child's care needs are being met?
6. What do you like least about how your child's care needs are being met?
7. What recommendations do you have about how to improve the system of care for their children with ADHD who live in rural setting?