

## **Children with Disabilities Involved with the Child Welfare System in Manitoba: Current and Future Challenges**

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There is growing awareness that children with disabilities are highly over-represented among those children who are reported for abuse and neglect (Fudge Schormans & Brown, 2006; Sullivan & Knutson, 2000). This over-representation may reflect a higher incidence of common risk factors for maltreatment among families with a child with a disability. These risk factors include poverty, parental substance misuse, social isolation, and stress (Krahn, Thom, Sokoloff, Hylton, & Steinberg, 2000). In addition, other factors contribute significantly to the risk of maltreatment for children with disabilities, such as the child's need for long-term care, inadequate supports, parent and child characteristics, and possible differences between parents' and professionals' understanding of the nature of the child's disability. Whatever the reasons for the over-representation of children with disabilities among those who are abused and/or neglected, their particular vulnerability is a critical child welfare issue.

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Not all children who are reported for or substantiated as being maltreated are placed in out-of-family care. However, there is evidence that children with disabilities are also over-represented among those who are placed in care (Fudge Schormans & Brown, 2006). Moreover, the number of children involved with mandated child welfare agencies who have medical, physical, intellectual, and mental health disabilities has increased dramatically over the past decade. Many of these children continue to be involved with the child welfare system, not because of an ongoing risk of maltreatment, but because they have intensive needs for care as a result of their disabilities, which communities and services are unable to fully meet (Cooke & Standen, 2002). The capacity of the child welfare system to respond to the service needs of this population group has become strained (Krahn et al., 2000). This is a serious social and economic concern (Sullivan & Knutson, 2000).

Despite increased recognition of these issues and risk factors, there has been little research aimed at developing a better understanding of the scope of the issue and the characteristics of the children requiring services (Horner-Johnson & Drum, 2006). This chapter begins to address this knowledge gap with results from an important research initiative in Manitoba, with much needed data on the growing number of children with a range of disabilities receiving services from both Aboriginal and non-Aboriginal child welfare agencies. "Children with Disabilities Receiving Services from Child Welfare Agencies in Manitoba" (Fuchs, Burnside, Marchenski, & Mudry, 2005), contributes to the interpretation and understanding of other study results in this area and provides a basis for interprovincial comparisons of Manitoba, Saskatchewan, and Alberta data.

In designing this study, the researchers adopted a broad approach to disability, including developmental delay, physical disabilities, and other disability disorders, with a particular emphasis on Fetal Alcohol Spectrum Disorder (FASD). Using this cross-disability approach and the World Health Organization (WHO) definition of disabilities, the study describes the population of children with disabilities who were involved with the child welfare system in Manitoba during the 2004/05 fiscal year. It also highlights some of the factors associated

with their involvement with the system. Specifically, this chapter presents:

- a profile of children with disabilities in care in Manitoba, including their number, distribution, nature of disabilities, care needs, and the services provided;
- a preliminary profile of children with disabilities involved with the child welfare system who use different forms of social services but who have not been placed in care; and
- implications of these findings for child and family service policy, programs, services, and training.

## **THEORETICAL CONTEXT OF THE STUDY**

The discussion of children with disabilities who are involved with the child welfare system must address the evolution of the concept of disability and the relationship between disability and the child welfare system. The following summary is intended to provide context as opposed to an in-depth analysis of these topics.

### **Evolution of the Concept of Disability**

The concept of disability has evolved over the past 50 years—from a medical model, through a functional model, to a social rights and ecological model. Disability is now almost universally understood to be the result of the interaction between an individual and the environment, rather than viewing the individual as the source of limitations. The World Health Organization (WHO) has been instrumental in establishing this perspective as the worldwide standard through the International Classification of Functioning, Disability and Health (ICF, 2006). In addition, the United Nations has enshrined children's rights to services, family support, and education, which serves to guide national policy on children's issues.

On the continuum of human ability, those who have difficulty in fully and independently participating in their various social contexts have been variously labelled, shunned, and marked as different or *the other* (Priestly, 2003). Our understanding of disability and treatment

of those so identified are part of a continuing evolution. (See, for example, Brown & Brown, 2003). Considerable progress has been made from the early 20th century, when illness and impairments were associated with shame, moral punishments, and living apart from society (Barnes & Mercer, 2003). The medical and functional models, although still useful for specific purposes, are no longer widely used because they emphasize personal deficits and limitations within the individual. The narrow definitions of normalcy prescribed by these models neglect to take into account social, economic, and attitudinal barriers faced by children with disabilities.

For the past decade, the ecological perspective has emerged as a useful theoretical framework for understanding the social construction of disability. Like the functional perspective, it is based on three distinct disability concepts: pathology, impairment, and disability. However, it sees disability as a result of the interaction between the person and the environment. This shift in emphasis from the individual limitations to the person-environment interaction can be clearly seen in the WHO amendments to the International Classification of Impairment, Disabilities and Health (ICIDH). For the first time, persons with disabilities and disability organizations were involved in developing the International Classification of Functioning, Disability and Health (ICF) system. The ICF conceptualizes disability as a complex phenomenon resulting from the interaction between health conditions and contextual factors (WHO, 2003).

An assessment of disability from the ecological perspective, therefore, involves "three levels of human functioning: at the level of the body or body part, at the level of the whole person, and the whole person in the social context" (WHO, 2002, p. 10). More recently, in response to advocacy by disability groups around the world, the WHO has extended its perspective to indicate that an assessment of disability must also examine the barriers to functioning that exist in social environments of persons with disability (Barnes & Mercer, 2003).

The ecological perspective provided the principal theoretical framework for this study, which had a particular interest in examining the individual, social, and environmental factors associated with childhood disability. The study was guided by the view that effective

measurement of childhood disability requires:

...consideration of the mediating role of developmental and environmental factors. A central issue is that children's environments change dramatically across stages of infancy, early childhood, middle childhood, and adolescence.... The influence of the environment on the child's performance and functioning is thus particularly important to document in this phase of the life-span. (Simeonsson et al., 2003, p. 605)

This research project also recognized the importance of the social rights model in developing its conceptual framework. The social rights perspective emphasizes not only that individuals with disabilities have the same rights as all other citizens, but that it is the responsibility of society to provide for and protect all of its citizens, including all "marginalized" citizens, in an equitable way (see Bach, 2003, and Rioux & Frazee, 2003). Simeonsson et al. (2003) suggested that the development of measures specific to the ICF to assess disability in children should be guided by a number of considerations—most importantly, the framework of children's rights. The publication of the United Nations *Convention on the Rights of the Child* in 1989 provided the initial guidelines for policy on children's issues. Key principles underlying the Convention include the child's right to be the first to receive services, to have his/her family protected, to have a family environment, to be protected from exploitation, and to receive education. The UN *Convention on the Rights of the Child* and the ICF complement one another: "One defines the rights of children and the second provides the framework for documenting the dimensions for which those rights are to be carried out" (Simeonsson et al., 2003, p. 606). Work is currently being carried out to develop a version of the ICF adapted specifically for children and youth (WHO, 2003).

### **Definitions and Prevalence of Disability**

Although it is clear that disability occurs everywhere, its precise prevalence is difficult to determine. Efforts are hampered by the vast array of disability definitions that make comparisons problematic.

Disabilities in children are particularly difficult to characterize because of the developmental nature of childhood. Although developmental delays or developmental disabilities are the most frequently noted type of disability, there is no standard definition of the elements of functioning encompassed by those terms (Betz et al., 2004). They may include physical impairments, sensory impairments, and intellectual disability.

The literature describes rates of developmental, sensory, and learning disabilities, as well as rates of psychological disorders and chronic health conditions. In Canada, the Participation and Activity Limitation Survey (PALS) conducted in 2001 provides national and local prevalence rates (Statistics Canada, 2002). According to PALS, the rate of disability in Manitoba (14.2%) was slightly higher than the national rate (12.4%). However, the rates of disability increased with age and the prevalence rates of children were reportedly low (1.6% for preschoolers and 4% for 5- to 14-year-olds). The rates of disability in the Aboriginal population were considerably higher than the national rates. The Aboriginal Peoples Survey (APS) cited a rate of 39.1% for children in Manitoba (Statistics Canada, 2001). (See also Brown & Percy, 2007 for a discussion of the prevalence of specific types of disabilities.) In Canada, Yu and Atkinson (2006) argued that it is reasonable to assume a prevalence rate of 2.25% for people with developmental disabilities. Statistics Canada (2002) reported that, among preschoolers with a disability, 68% had a developmental disability. Of those, 59% had an intellectual disability, 54% had a physical disability, and 38% had another type of disability. Among school-aged children with disabilities, 29.8% had a developmental disability and 31.8% had a psychological disorder. The likelihood of children in care having attention deficit or attention deficit hyperactivity disorder (ADHD) was at least three times that of children not in care (Martens et al., 2004). FASD, a serious social and health problem, is considered the most common cause of preventable intellectual disability. The incidence in Manitoba has been estimated from 7.2 per 1,000 live births (Williams, Odaibo, & McGee, 1999) to as high as 101 per 1,000 live births (Square, 1997).

### **Disability and the Child Welfare System**

There is considerable evidence that children with disabilities are at increased risk of abuse and/or neglect. Crosse, Kaye, and Ratnofsky (1993) found that in the United States, children with disabilities were 1.7 times more likely to be abused than children without disabilities. Sullivan and Knutson (2000) completed a study in Omaha, Nebraska with a sample of 50,278 children between the ages of birth to 21 years. They identified 4,503 children who were maltreated (physical, emotional, or sexual abuse and/or neglect). Of those children who were maltreated, 1,012 had a disability. For non-disabled children, the rate of maltreatment was 11%, while the rate for disabled children was 31%. In other words, children with a disability were 3.4 times more likely to be maltreated than non-disabled children.

As part of this study, Sullivan and Knutson (2000) also compared children by type of disability to non-disabled children in terms of their risk for the four types of maltreatment they identified. Children with behavioural disorders were found to be at the highest risk of abuse. They were seven times more likely to be neglected, and/or to be physically or emotionally abused, and five and a half times more likely to be sexually abused. Speech and language difficulties resulted in five times the risk of disabled children experiencing neglect and physical abuse, and three times the risk of being sexually abused. Children with a developmental delay had four times the risk of all four types of maltreatment. Deaf and hard of hearing children had twice the risk of being neglected or emotionally abused and were almost four times more likely to be physically abused. Children with learning and orthopedic disabilities had twice the risk of all types of neglect.

A study by Sullivan, Knutson, Scanlan, and Cork (as cited in Krahn et al., 2000) also found that children with a disability were more likely to be abused or neglected. Specifically, they were 1.6 times more likely to be physically abused, 2.2 times more likely to be sexually abused, and 1.8 times more likely to be neglected. In addition, the risk of abuse for these children increased if they had multiple disabilities. In Oregon, Krahn et al. (2000) found that the presence of a disability increased the effects of poverty, social isolation, and stress on the likelihood of abuse occurring.

Cooke and Standen (2002) completed a study on abused and neglected children in the United Kingdom. Questionnaires were sent to the 121 chairs of the area child protection committees. Information from the 73 who responded demonstrated that there was a lack of statistical information on children with disabilities involved with child protection committees. Children with disabilities were less likely than children without disabilities to be put on the registry of child victims. From their study, Cooke and Standen made a number of recommendations to address the risk of child maltreatment faced by children with disabilities. These included: 1) recording and computer forms that allow child protection and child disability teams to identify children with disabilities being investigated for abuse; 2) using a computer system that can effectively extract statistical information on abused, disabled children; 3) creating training programs for staff members on abuse awareness, definition of disability, and forms of recording; and 4) creating a clearly defined protocol to ensure better communication between child protection teams and child disability teams.

Fudge Schormans and Brown (2006) analyzed data from the 1998 Canadian Incidence Study on Reported Child Abuse and Neglect (Trocmé et al., 2001) to report on children with developmental delay who had experienced substantiated maltreatment. They compared 666 children with developmental delay and 7,006 children with no delay and found that the children with delay made up 8.68% of all those maltreated. This over-representation—approximately three times as many as would be expected from population prevalence—was associated with increases in child behaviour problems, risk factors of main caregivers (e.g., alcohol and drug use, mental health problems), and poor socio-economic conditions for the children with developmental delay. Sexual abuse was the least common type of maltreatment among children with and without delay. Neglect was the most common form of maltreatment and the rates were higher among children with delays than those with no delays. The study also found that biological mothers and fathers were the perpetrators in more than 90% of cases of reported and confirmed maltreatment, and that children with developmental delay were more likely than children with no delay to be placed in out-of-home care following a maltreatment investigation by social workers.

When examining family factors that influence out-of-home placement decisions, Llewellyn, Dunn, Fante, Turnbull, and Grace (1999) examined the experiences of 167 families with children with disabilities requiring a high level of support. To be eligible for placement, a family had to have a child between the ages of birth to six years with a physical, intellectual, sensory, or multiple disability. Additionally, parents and/or service providers could identify the child as having a high need for supports, which the general child service system was unable to meet.

The researchers identified three types of families: those who did not want to place their child (75%), those who were undecided (19%), and those who were actively seeking or had already sought a placement (6%) (Llewellyn et al., 1999). There was no difference among the three types of families in terms of being proactive, finances, father's involvement, mother's availability, and religion. There was, however, a difference in terms of values and beliefs about caring for the child, changes in family circumstances, and messages received about out-of-home placement.

It is worthy of note that Manitoba's *Child and Family Services Act* (1985) provides an incentive for bringing children into the care of the child welfare system. It makes special provision for children with disabilities through the Voluntary Placement Agreement (VPA). Children with disabilities may be voluntarily placed in the care of an agency to access services or obtain care that parents are unable to provide. Placement may be renewed until the age of majority, and the parents maintain guardianship throughout the length of placement. Although this assists in keeping parents involved to some extent in the care of the children, it requires that families with children with disabilities receive service from a system that is set up to deal with child maltreatment, and not disability support for families.

In summary, disability occurs as a consequence of the interaction of the individual and his or her environment. The literature presents a somewhat confusing picture of the prevalence of disability in children in Manitoba. There does, however, appear to be a significantly higher rate of disability among Aboriginal children, compared to the general population. It is clear that many children have disabilities that are reflected in their intellectual, psychological, physical, medical, and/or sensory functioning. Developmental delays and psychological

disorders are the most commonly described disabilities in children. Multiple disabilities affect the majority of children with disabilities. Unfortunately, children with disabilities are at increased risk of abuse and neglect.

The needs of children with disabilities create significant challenges for child welfare agencies in Manitoba. The number of children with disabilities and their demands on care systems have increased as medical advances have reduced the mortality rate, and increased the longevity of children with complex medical needs. Because of additional risk factors associated with disability, these already vulnerable children have a greater potential than other children for requiring the support or protection of a child welfare agency.

### **CONCEPTUALIZATION OF DISABILITY**

Disability research often becomes mired in issues relating to the definition of disability. Consequently, establishing the parameters of disability for the purposes of this study was a critical first task. The definition had to be:

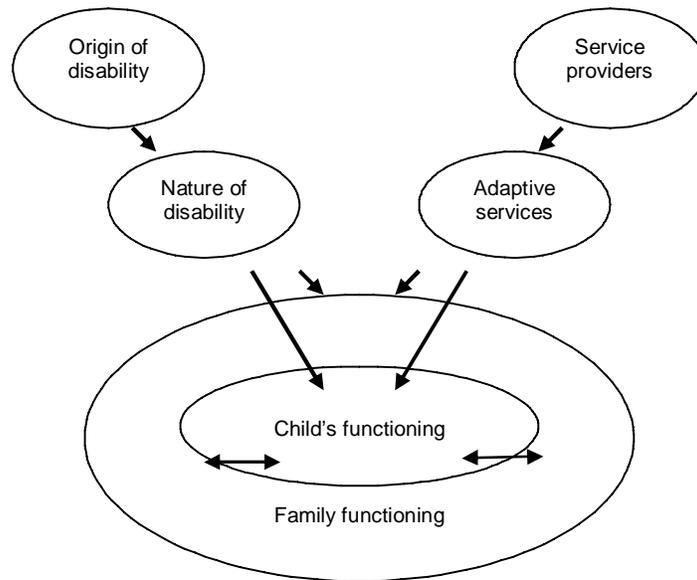
- broad, to capture a wide enough sample to provide as much information as possible (i.e., present the "big picture");
- concise, to be easily interpreted and consistently understood by a variety of workers and agencies; and
- relevant, to recognize current thinking in the field of disability so that results were meaningful and comparable to existing and future research studies.

The definition of disability that was developed did not attempt to classify children, but to describe their health in the context of personal and environmental factors. Therefore, this study defined children with disabilities as those whose ability to participate in age-appropriate activities of daily living is compromised by limitations in one or more areas of functioning. Disability and functioning included physical, medical, sensory, intellectual, and mental health components.

More specifically, the definition included children with congenital conditions (e.g., spina bifida, Down syndrome), as well as chil-

dren who have experienced life-changing illness or injury. It included children with complex medical needs and those with chronic psychological or mental health concerns. It also included children with FASD and learning disabilities. By definition, children with disabilities require adaptations to their environment to meet their special needs.

Using this definition, which was intended to conform to the WHO understanding of disability, a conceptual framework was developed (see Figure 1). This framework conceptualized disability as one of the factors affecting the functioning of a child and his/her family. Functioning was also influenced by adaptive services and service providers (Brown, Moraes, & Mayhew, 2005). For the purposes of this study, adaptive services were comprised of medical, mechanical, technical, and personal support. These elements were chosen because they are the types of services offered and recorded by child and family service agencies.



**Figure 1: Conceptual framework of disability**

**Table 1: Components of factors related to functioning**

Factor	Components	
Origin of disability	Genetic Medical	Injury Substance abuse
Nature of disability	Physical Medical Sensory perceptual	Cognitive intellectual Mental health
Functioning and service needs	Physical Medical Sensory perceptual	Cognitive intellectual Mental health Behavioural
Adaptive services	Medical Mechanical	Technical Support
Service providers	Government Non-government	

Components of the factors related to the child's functioning are highlighted in Table 1.

Plans for the care of children with disabilities always included adaptations to the environment (e.g., home, school, community) that were necessary to meet their special needs. Environmental adaptations might be described as medical care (e.g., essential medication routines, physiotherapy), mechanical aids (e.g., wheelchairs, prostheses), technical devices (e.g., communication aids, computer programs), and/or personal support services (e.g., 24-hour supervision or in-home support workers).

Excluded from the study were children who required special care as a result of difficult to manage behaviour that was not related to a diagnosable condition.

## METHODOLOGY

Because of the dearth of research in this area, this study employed an exploratory and descriptive research design. The choice of research design was dictated by the need for a descriptive profile of children with disabilities who were involved with child welfare agencies in

Manitoba, as well as the limitations of the available databases. A data collection instrument was developed to gather information in each of the areas outlined by the conceptual framework. Because the project relied entirely on the information available in agency files, the data collection instrument was also shaped by the existing child welfare information gathering system.

Data collection took place between October 2004 and June 2005. Agencies throughout the province were asked to identify children who were receiving services on September 1, 2004 and who met the study's definition of disability. They were also asked to identify children who were not in care but whose families were currently receiving services. Research staff then visited each agency and reviewed the files of the children identified. A review of randomly selected files on children in care at each site served to check the accuracy with which agencies applied the disability definition. Agencies that participated in the data collection process represented 90% of the children in care and the resulting database is reflective of children in all regions of Manitoba: rural and urban, and north, south, and central Manitoba.

## **PROFILES OF CHILDREN IN CARE WITH DISABILITIES**

The profiles of children with disabilities created by this research present a demographic description of the population and illustrate the nature and origin of disabilities, the functioning of children, and the adaptive services they received from child welfare agencies and other sources.

Using the definition outlined above, one-third ( $n=1,869$ ) of children in care in Manitoba on September 1, 2004 were found to have a disability. The children ranged in age from birth to 20 years with a mean age of 10.5 years. Boys accounted for 60% and girls for 40% of the children with disabilities in care. The higher proportion of boys was consistent across cultures of origin. The number of children with disabilities increased with age until 13 years when the numbers of both boys and girls began to decline. First Nations children comprised just over two-thirds (68.7%) of children with disabilities in care. Their representation within the disability population approxi-

mated their over-representation in the overall children in care population. Most children with disabilities were permanent wards of the state (69%) but a significant proportion (13%) were in care under a Voluntary Placement Agreement (VPA). The proportion of permanent wards was somewhat greater among First Nations children. The most frequently cited reasons for children with disabilities coming into care were related to the conduct or condition of their parents. Children in care under a VPA were the exception. Approximately half of those children were in care for reasons related to the conduct or condition of the child. Most children (75%) were placed in foster homes, and only 2% required hospital or residential care at the time of data collection. The proportion of children requiring more intensive care was greater among those under a VPA (41%), than among those who were permanent wards (16%).

A comparison of the demographics of children with disabilities and the general population of children in care revealed that children with disabilities were more often older, male, and permanent wards, than children without disabilities.

Disabilities were ordered in six main categories: intellectual, mental health, medical, physical, sensory, and learning. The most common disabilities were intellectual, which affected 75.1% of the children with disabilities, and mental health (45.8%). More than half the children had more than one type of disability (58.1%) and the most common combination of disabilities was, again, intellectual and mental health. FASD was diagnosed in one-third of children with disabilities (34.2%) or 11% of all children in care. Children with a mental health diagnosis were almost always (95%) given a diagnosis that fell in the attention deficit/disruptive behaviour disorders group. Attention deficit disorders were the most frequently diagnosed (73%). FASD and attention deficit hyperactivity disorder (ADHD) were comorbid (occurred together) in 39.1% of children with an FASD diagnosis. The remaining disability types affected smaller proportions of children with disabilities: medical disabilities (22%), physical disabilities (18%), sensory disabilities (5%), and diagnosed learning disabilities (3%).

The majority of disabilities resulted from an unknown cause. Maternal substance abuse was reported as the origin of disability for 34.3% of the disability population, and was a suspected cause for an

additional 17.3% of those children.

To support functioning, 25.1% of the children needed assistance with the activities of daily living and 42.2% required medical support, as described by the Unified Referral and Intake System. The majority of children were not age appropriate in language (55.1%) or learning (62.8%). Of those with mental health disabilities, 84.4% required medication. Most children with disabilities were not able to achieve age-appropriate behaviour in dependability (76.4%), emotional modulation (72.0%), interpersonal interaction (64.4%), or awareness of risk (58.6%). Aggressive behaviour was problematic for 43% of children with disabilities. Other problem behaviours included sexually inappropriate behaviour, involving 15.7% ( $n=294$ ), and conflict with the law, involving 11.3% ( $n=212$ ).

The most frequently noted adaptation was medication, which was provided for 47.8% of children. Children with multiple disabilities were the most frequent recipients of services. Many organizations and agencies outside of child and family services (CFS) assisted in supporting children with disabilities. The greatest contributor was the education system, which provided some form of additional support to more than 50% of children. CFS was the second most frequent additional service provider, purchasing extra services for 18.5% of children with disabilities.

## **MAJOR IMPLICATIONS OF THE STUDY**

The findings of this study have significant implications for policy makers and practitioners in contact with children with disabilities in the child welfare system.

The study demonstrated that children with disabilities are a significant proportion of the children in care in Manitoba. Currently, the child welfare system is not well structured to serve children with disabilities and their families. The data indicate that many children with disabilities and their families are not receiving the services necessary to meet their needs from the child welfare or other service systems. To ensure that these children and their families receive the services they require, awareness of their needs and knowledge of how to address them must be the foundation of policy, program planning, staff training, and service provision.

The large number of families of children with disabilities coming to the attention of the child welfare system represent significant social and economic costs. Greater understanding, sensitivity, and awareness within the child welfare system is needed to more effectively address the issues and needs of families and children with disabilities.

Approximately one-third of Manitoba's children in care have a disability and most of these children have multiple disabilities. The culture of origin of children with disabilities was reflective of the general population of children in care, including the over-representation of Aboriginal children.

The highest proportion of mental health, medical, physical, and sensory disabilities was found among the non-Aboriginal population, but there were substantially higher numbers of Aboriginal children with all types of disabilities in care. First Nations children had the highest rate of intellectual disabilities and the lowest rate of mental health disabilities. Among the non-Aboriginal group, the opposite was true.

Slightly more than one-third of children with disabilities had FASD and slightly more than half had suspected FASD. In most cases, children had co-occurring disabilities; the most frequently combination being intellectual and mental health disabilities, such as FASD with ADHD.

Maternal substance abuse during pregnancy was the cause of approximately one-third of disabilities. If suspected FASD is included, just over half of the children had a disability as a result of substance abuse. Prenatal substance abuse is a totally preventable cause of disability. If FASD could be fully prevented, the number of children in care with disabilities would shrink up to one-third.

A large number of children received adaptations and supports, particularly medication and personal supports. Most children were not functioning at an age-appropriate level in terms of personal and social behaviour.

The findings of this study have significant implications for policy makers and practitioners. The study demonstrates that children with disabilities are a significant proportion of the children in care in Manitoba but the child welfare system is not well structured to serve children with disabilities and their families. Many such children and

families are not receiving the services they need from any system. A better awareness of their needs and knowledge of how to address them must inform policy, program planning, staff training, and service provision.

The study also demonstrates the importance of research related to children with disabilities and child welfare. The data provides a baseline for future research and makes a significant knowledge contribution but also points to the urgent need for additional research to inform professional training and service development, and to promote safety, accessibility, and social inclusion for families and children with disabilities.

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