Bridging the Gaps

Achieving Substantive Equality for Children with Disabilities in Manitoba

A SPECIAL REPORT BY THE MANITOBA ADVOCATE
FOR CHILDREN AND YOUTH, 2021

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ABOUT OUR OFFICE

The Manitoba Advocate for Children and Youth is an independent, non-partisan office of the Manitoba Legislative Assembly. We represent the rights, interests, and viewpoints of children, youth, and young adults throughout Manitoba who are receiving, or should be receiving, provincial public services. We do this by providing direct advocacy support to young people and their families, by reviewing public service delivery after the death of a child, and by conducting child-centred research regarding the effectiveness of public services in Manitoba. The Manitoba Advocate is empowered by legislation to make recommendations to improve the effectiveness and responsiveness of services provided to children, youth, and young adults. We are mandated through *The Advocate for Children and Youth Act* (ACYA) and guided by the *United Nations Convention on the Rights of the Child* (UNCRC), and we act in accordance with the best interests of children and youth.

Our Vision: A safe and healthy society that hears, includes, values, and protects all children, youth, and young adults.
Our Mission: We amplify the voices and champion the rights of children, youth, and young adults.
Our Values: Child-Centredness; Equity; Respect; Accountability; Independence

Our Commitment to Reconciliation

The mandate of our office extends throughout the province of Manitoba and we therefore travel and work on a number of treaty areas. Our offices in southern Manitoba are on Treaty 1 land, and our northern office is on Treaty 5 land. The services we provide to children, youth, young adults, and their families extend throughout the province and throughout Treaty areas 1, 2, 3, 4, 5, 6, and 10, which are the traditional territories of the Anishnaabeg, Cree, Oji-Cree, Dakota, and Dene peoples, and the beautiful homeland of the Metis nation.

As an organization, we are committed to the principles of decolonization and reconciliation. We strive to contribute in meaningful ways to improve the lives of all children, youth, and young adults, but especially to the lives of First Nations, Metis, and Inuit young people, who continue to be disproportionately impacted by systemic inequalities and other barriers in our communities.

With a commitment to social justice and through a rights-based lens, as an office we integrate the *United Nations Convention on the Rights of the Child*, the *United Nations Declaration on the Rights of Indigenous Peoples,* and the national Truth and Reconciliation Commission's *Calls to Action* into our practice. Our hope is that the scope of our work on behalf of children, youth, young adults, and their families contributes to amplifying these voices and results in tangible improvements to their lives and outcomes.

Dedication and Acknowledgements

This special report is dedicated to all the children with disabilities in Manitoba and their families who seek out and speak about the services they need.

With this special report, we honour the life of Emma.

The Manitoba Advocate for Children and Youth wishes to give special thanks to the following individuals: Dr. Richard Antonelli (Assistant Professor, Harvard Medical School and Medical Director of Boston Integrated Care Organization), Dr. James Anglin (Professor Emeritus, School of Child and Youth Care, University of Victoria), Tracy Moore (Disability Services Consultant), and Pascal Lambert (Statistician). We would like to acknowledge the important efforts of disability services, health, education, and child welfare professionals across the province, who are involved in providing care and support for children, youth, caregivers, and their families. Thank you for your work and dedication to upholding children's rights.

Above all, we thank the hundreds of caregivers who participated in our survey and consultations, sharing their experiences and struggles so that services can improve for everyone.

“I look for an ounce of empathy every time. People making these decisions need to know what it is actually like for families to have a young person living with a disability.”

– Parent Interview

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Abbreviations

ACYA	*The Advocate for Children and Youth Act*
CdS	Children's disABILITY Services
CFS	Child and Family Services
CFSA	*The Child and Family Services Act*
CFSIS	Child and Family Services Information System
CIC	Child in Care
CLdS	Community Living disABILITY Services
CRPD	*Convention on the Rights of Persons with Disabilities*
CTI	Children's Therapy Initiative
DHSU	Disability and Health Supports Unit
EA	Education Assistant
FSW	Family Service Worker
IHCP	Individual Health Care Plan
IEP	Individual Education Plan
OT	Occupational Therapy/Therapist
PPD	Provincial Placement Desk
PT	Physiotherapy/therapist
SLP	Speech Language Pathology/Pathologist
UNCRC	*United Nations Convention on the Rights of the Child*
URIS	Unified Referral Intake System
VPA	Voluntary Placement Agreement

Message from the Manitoba Advocate

Ainsley Krone
A/Manitoba Advocate for Children and Youth

Children with disabilities and their families in our province have fundamental human rights. In my role as the Acting Manitoba Advocate for Children and Youth, it is my responsibility to raise awareness and understanding of these inherent rights outlined in the *United Nations Convention on the Rights of the Child* (UNCRC) and the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD). This special report marks the first time the children's disability services system of Manitoba has been systematically and independently reviewed by my office.

This special report is grounded by the story of a child we call Emma. Emma was a happy child who lived in rural Manitoba for most of her life. Those who knew her enjoyed her personality and spirit. Emma lived with disabilities and challenges that impacted her mobility, behaviour, and overall independence. Children's disABILITY Services (CdS) was active in providing services, including case management, respite, occupational therapy, and psychiatry supports. She also received support to attend school and participate in her community, including through mobility aides and assistance.

As Emma aged, her health conditions and associated behaviours escalated. Her natural supports grew more and more exhausted and overwhelmed. Accessing and finding respite was difficult. Indeed, her family had to pay out-of-pocket for respite supports, and contacted the Ministers of Families and Health on two occasions, pleading for help. CdS, having also surpassed its alloted resources and mandate, brought Child and Family Services (CFS) in to plan for a specialized placement and provide support for the family. CFS does not operate under the same fiscal and mandate constraints that CdS does, even though both service areas are under the same provincial department. In the months before the tragic accident that resulted in Emma's death, CdS and CFS were unable to coordinate services effectively to meet the needs of Emma and her family.

In accordance with international law and Canadian legal principles of non-discrimination, children and youth with disabilities in Manitoba have the right to effective government services that ensure substantive equality. That means children like Emma are entitled to equality in outcomes and the resources necessary to ensure they can realize their rights. Families of children with disabilities have the right to receive appropriate supports to maintain family life and prevent separation.

The findings and recommendations I am releasing today are informed by a child death investigation, statistical analysis of CdS and CFS administrative data, a survey with caregivers of children with disabilities, interviews with children and youth with disabilities, and extensive consultations with service providers, stakeholders, and experts in the field of disability services for young people. Approximately 400 children, youth, caregivers, and service providers have participated in this special report.

Manitoba families are struggling. What you will read in this special report is that Manitoba's services for children with disabilities are underfunded and under resourced. This is not just the case for children with complex medical and behavioural needs, like Emma. Our caregiver survey and consultations with parents reveal that gaps in service exist for many children with disabilities and their families. Families who can, pay out-of-pocket for supports. Yet families that experience multiple layers of disadvantage struggle more, including Indigenous caregivers and single parent households. Some children with disabilities may enter the care of child welfare in order to receive services even when no child protection concerns exist.

Informed by Emma's child death investigation, our findings are presented in four key theme service areas: (1) case management; (2) respite care; (3) alternative care; and (4) child welfare system involvement. What we found is that each of these themes explored through the report are interrelated.

Long wait-times for diagnostic assessments, combined with wait-times for CdS case managers and large caseloads present multiple barriers to access services for families. What we heard from caregivers across Manitoba is that our province has skilled workers who are dedicated and hardworking for families, but that more time is needed to build relationships between families and the workers who support them. Children and youth echoed this by describing better relationships means they feel more heard and understood, which is their right. Caseloads that average 133 families translate to less contact with families and, in turn, may lead to less proactive case planning.

The number and proportion of Manitoba families receiving respite through CdS has decreased every year for the past five years. Families who are able, often pay out-of-pocket for supports or to supplement the income of respite workers. As was the case for Emma, when needs escalate or circumstances change, families can find themselves in a crisis with nowhere to turn for supports and resources. There is no one size fits all model that works for everyone. The evidence we present in this special report makes it clear that additional and flexible respite options are needed.

Alternative care options outside the home are rare in Manitoba. Some families identified a need for either full-time or part-time alternative out-of-home care as a way to receive respite. Our review found that there are few options available, and for those that exist, wait-times can be long. This is when the child welfare system may come in. Child welfare, unlike CdS, has the ability to license specialized placements; however, this means children must enter child welfare care.

There is a significant overlap between the disability and child welfare systems in Manitoba. Over a period of five years, 47% of children enrolled in CdS had contact with the child welfare system. Of them, one in four formally entered care. To understand the reasons, we reviewed the cases of 53 children with disabilities that entered care in 2019-20. Problematically, we found that for 36% of children that entered care of CFS, their disability was a contributing factor. This finding runs contrary to the right of children with disabilities not to be separated from parents because of their disability (Article 23.4, CRPD). Entry into child welfare care can be prevented with the right supports.

A fundamental shift in the allocation of resources for children with disabilities is needed to ensure substantive equality. This shift can begin from our collective commitment that children and youth with disabilities are entitled to care and services that view them as equal members of the community and assist them in achieving their full potential. Knowing that all children are best cared for by their own families, investments are needed in our province to prevent entry to CFS care, when no child protection concerns exist.

The evidence is abundantly clear that such a shift is good for families and is also good value for money. Indeed, cost-effectiveness analyses demonstrate that shortening wait times and increasing early interventions for children with disabilities is a win-win-win for children, their caregivers, and taxpayers (see page 85).

Today, I make nine recommendations to increase the effectiveness and responsiveness of disability services for children in Manitoba.

First, I am calling on the Manitoba government to enact new legislation to govern services for children with disabilities and their families. Many of the systemic issues we identified were tied to the absence of a legislative mandate for CdS that would empower the development of a continuum of services. Creating legislation that empowers those with expertise in disability care to oversee those services is essential to ensure children are not unnecessarily entering child welfare care due to gaps in a CdS mandate. Second, for children that need protection services though the child welfare system, I recommend the development of a Department of Families protocol that coordinates services between its two key streams: child welfare and Children's disABILITY Services.

Third, I recommend that wait-times for diagnostic assessments be reduced by resourcing a strategy to recruit and hire professionals with the long-term goal of limiting wait-times to a maximum of six months. While this strategy is being developed, I recommend establishing system navigation supports for families to ensure they are connected to available services at the earliest opportunity.

Fifth, I recommend a rigorous review and analysis of case management workload and caseloads at CdS to ensure that its current staffing levels are sufficient to meet the best practice standards already in place at the department. Sixth, it is essential to understand and respond to the cultural needs of children with disabilities, to do this, more accurate information about First Nation, Metis, and Inuit ancestry is needed in order to provide services that are culturally sensitive.

Seventh, I recommend that the voices of children with disabilities and their families be at the centre of service provision through the development of processes to gather regular feedback. Aligned with this, I also recommend that all CdS policies and procedures be made public to enhance communication and transparency.

Finally, recommendation nine is about developing and resourcing a full continuum of flexible respite support for families. Respite is crucial for the families of children with disabilities and must be implemented in uncomplicated and flexible ways to meet families where they are at.

What became abundantly clear from speaking with caregivers is while families told us that workers inside the disabilities system are skilled, knowledgeable, and supportive, resources are scarce and are stretched too thin. As a result, families are struggling with the services that are available to them. Further, while the global pandemic has worsened existing service gaps, the challenges are not new. The Government of Manitoba has an opportunity to invest in transformative improvements that realize the rights of children with disabilities in Manitoba and maximize value for money. There are gaps in the services and it is my hope that this special report supports the development of bridges towards substantive equality.

Ainsley Krone MA PC-IIC, RSW
A/Manitoba Advocate for Children and Youth

Recommendations Summary

Enact a new law to provide a continuum of supports and services for children with disabilities and their families that is in line with their rights

Develop a protocol with child welfare to coordinate services, when needed

Fund a plan to reduce wait-times for diagnostic assessments

Develop systems navigation supports for families while on wait-lists

Review and address case management caseloads

Improve accuracy of data about First Nation, Metis, and Inuit children

Gather regular feedback from children and families on services

Make a policies and procedures manual available to the public

Establish a full continuum of respite supports for families

> **“States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child’s active participation in the community.”**
>
> – Article 23 of the *United Nations Convention on the Rights of the Child*

Section 1: Introduction

Every Manitoba child living with disabilities has rights that are clearly articulated in the *United Nations Convention on the Rights of the Child* (UNCRC) and the *Convention on the Rights of Persons with Disabilities* (CRPD). By ratifying both treaties, Canada – and by extension, Manitoba – has committed to fulfilling the rights of all Canadian children living with disabilities. This special report focuses on the following obligations:

- To ensure children with disabilities are free from discrimination (*Canadian Charter of Rights and Freedoms*, *Canadian Human Rights Act*, UNCRC, and CRPD).
- To ensure children with disabilities live a full and decent life with dignity, self-reliance, and active participation in the community (Article 23, UNCRC).
- To ensure that children with disabilities have equal rights with respect to family life, including the right to prevent concealment, abandonment, neglect, and segregation of children with disabilities, by providing early and comprehensive information, services, and support to children with disabilities and their families (Article 23.3, CRPD).
- To ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child (Article 23.4, CRPD).
- To undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting in cases where the immediate family is unable to care for a child with disabilities (Article 23.5, CRPD).

Despite significant advancements over the last few decades in Manitoba, children with disabilities and their caregivers continue to face barriers to the full enjoyment of these rights. These barriers represent a combination of the social, cultural, attitudinal, and physical obstacles that children with disabilities and their families encounter everyday (UNICEF, 2021; CRC/C/G/9).

The inequities children with disabilities experience are more pronounced when children are exposed to additional and overlapping levels of systemic discrimination based on race, ethnicity, sexual orientation, class, or gender identity. For instance, First Nations, Metis, and Inuit children in Canada living with disabilities are often subjected to jurisdictional disputes that have led to additional barriers to fulfilling their rights to health and social services. Furthermore, too often First Nations children living on- or off-reserve are denied or left waiting for the services they need. Access to public services such as health, education, childcare, recreation, culture, and language should be available without any service denials, delays, or disruptions, in a way that reflects distinct First Nations cultural needs and redresses historical disadvantages that stem from colonization.

Rationale

In 2017, the Manitoba Advocate received notification of the accidental death of a child we call Emma, a child with disabilities, from the Office of the Chief Medical Examiner as per section 10(1) of *The Fatality Inquiries Act* (FIA). Because Emma's family had been involved with the child welfare system through a voluntary family services file at the time of her death, a review of the services provided to Emma and her family was completed under Section 8 of *The Child and Family Services Act*. When *The Advocate for Children and Youth Act* (ACYA) was proclaimed in 2018, the review expanded and progressed to a full investigation under Section 23(1)(a) of the ACYA. Our review revealed important gaps in disability and child welfare services which may have contributed to Emma's death.

Motivated by the death of Emma and empowered by new legislation introduced in 2018, the Manitoba Advocate directed the launch of this child death investigation and special report under Part 4 and Part 5 of the ACYA. This special report marks the first time the children's disability services system of Manitoba has been systemically and independently reviewed by this office. The review into the death of Emma informed the scope of this special report, which explores the following key theme areas:

(1) Case management
(2) Respite services
(3) Alternative care
(4) Child welfare system involvement

This is not an exhaustive list of the issues affecting children living with disabilities and their families. Through the work of MACY's programs, including the Advocacy Services Program, the Manitoba Advocate continues to respond to concerns affecting children living with disabilities and their families, including services provided to children with disabilities in schools and transitions to adult services.

Purpose

This report aims to assess services provided to children and youth with disabilities and their families based on their entitlements as outlined in Canadian and international law. All children living with disabilities have the right to full participation in society. Furthermore, they have the right to effective government services that ensure **substantive equality.** The purpose of this special report is:

1. To raise awareness and understanding of the inherent rights of children living with disabilities in Manitoba (ACYA, s.12), and;
2. To develop recommendations that increase the effectiveness and responsiveness of disability services for children in Manitoba (ACYA, s.31(1)).

> **"Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others."**
>
> *— United Nations Convention on the Rights of Persons with Disabilities*

Section 2: Background

How Many Children Live with Disabilities?

Statistical information on children living with disabilities is often incomplete or dated. Nevertheless, UNICEF estimates that at least 93 million children live with a disability worldwide (UNICEF, 2021). In Canada, 27,540 (1.7%) children from birth to 4 years of age and 174,810 (4.6%) of children between the ages of five and 14 were noted to be living with a disability (Human Resources and Skills Development Canada, 2013). An estimated 13% of Canadian youth between 15 and 24 years old have one or more disabilities (Statistics Canada, 2018).

Although the total number of children living with disabilities in Manitoba is unknown, during the 2019-20 fiscal year approximately 6,000 children and youth under 18 years of age were enrolled in Children's disABILITY Services – a central disability services program in Manitoba.

What is Disability?

The language and terms used are very important to a collective understanding of disability. Still, numerous definitions and ways of describing disabilities are used in legislation and by governments and organizations who serve children with disabilities.

The most widely used definition of disability comes from the World Health Organization (2020):

"Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure, an activity limitation is a difficulty encountered by an individual in executing a task or action, while a participation restriction is a problem experienced by an individual in involvement in life situations."

A disability may be present from birth or be the result of an accident or illness; some are visible (e.g., a physical limitation), while others may be hidden from view (e.g., a learning disability). Whatever the cause or however visible, it is clear that any disability may have a profound effect on a young person's ability to fully participate in daily activities (Manitoba Ombudsman, 2011).

While there is no standard federal definition of disability in Canada, the Supreme Court of Canada validated the social model of disability (Human Resources and Skills Development Canada, 2013). The social model of disability understands disability not only as a medical condition, but a social one as well. Judicial decisions reaffirm disabilities may be the result of "physical limitations, an ailment, a social construct, a perceived limitation, or a combination of all these factors" (Comission des droits de la personne et des droits de la jeunesse, 2000). This is the standard applied by the Manitoba Human Rights Commission (Manitoba Human Rights Commission, 2010).

The definition of disability included in Manitoba laws is narrow. "Mental disability" is defined as "impaired intellectual functioning together with impaired adaptive behaviour that manifests prior to the age of 18" (*The Vulnerable Persons Living with a Mental Disability Act*, 1993). This definition, however, excludes "mental disorders" defined as a "substantial disorder of thinking, mood, perception orientation or memory that grossly impairs judgement, behaviour, and capacity to recognize reality or ability to meet the demands of ordinary life" (*The Mental Health Act*, 1998).

Who Delivers Disability Services for Children in Manitoba?

The mandate to provide services for children with disabilities (under 18 years old) and their families is shared primarily by three different departments: Families, Education, and Health and Seniors Care. Some services are delivered through regional health authorities, school divisions, schools, and non-profit organizations.

The Department of Families plays a major role in providing non-medical disability services for children and youth. In the Department of Families, the following programs, divisions, departments, and units provide services to children with disabilities and their families:

1. **Children's disABILITY Services (CdS):** provides a range of services and supports for children with disabilities who live at home with their families, including case management, respite, and behavioural psychology services.
2. **Child and Family Services (CFS):** provides family enhancement supports, voluntary surrender of care or Voluntary Placement Agreements, and licensing of placements.
3. **Disability and Health Supports Unit (DHSU):** provides assessment and approval of medical supplies and equipment for children and adults with disabilities.
4. **Early Learning and Childcare Division:** provides licensing of early learning and childcare, and supports for children with disabilities through the Child Care Inclusion Support Program.

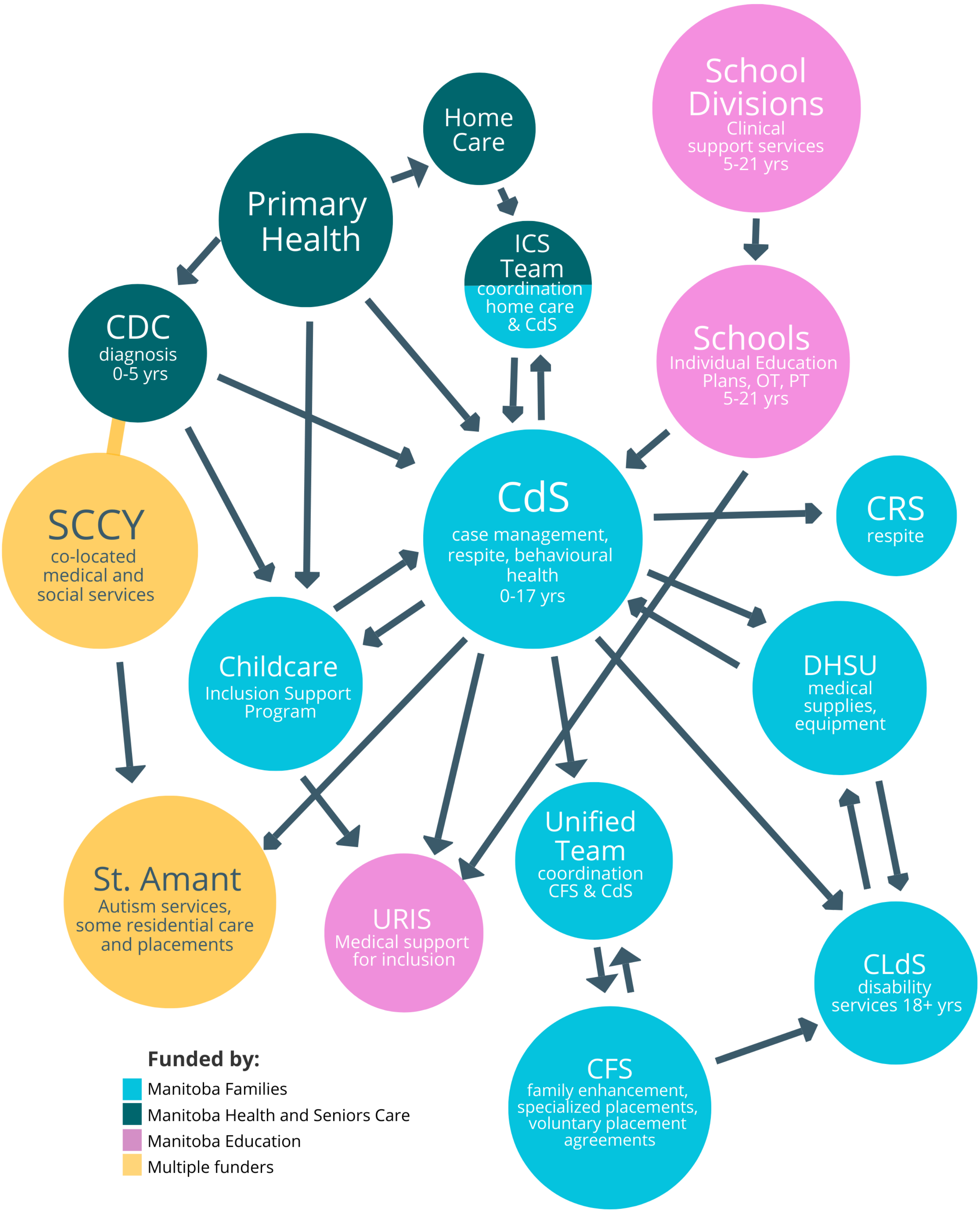
Figure 1 (next page) demonstrates the complexity of the children's disability system in Manitoba and illustrates the challenges families and caregivers may face when navigating the services and supports their children with disabilities are entitled to receive. Of note, the figure also shows the central role that CdS plays and how well positioned it is within the system to support systems navigation and connect families to services. A detailed list of departmental responsibilities, funding structures, and ages served for the Departments of Families, Education, and Health and Seniors Care can be found in Appendix A (Online Supplement).

Legal Framework

The provincial legal framework for disability services for children is complex. There are at least 12 separate provincial acts with accompanying regulations that frame services for children with disabilities and their families (Appendix B in the Online Supplement). Manitoba does not have stand-alone legislation to govern programs and services provided to children living with disabilities and their families. This means that CdS does not have formal legal authority.

In 2004, Alberta became the first province in Canada to proclaim an Act specific to the provision of services for children with disabilities and their families (Province of Alberta, 2017). Previously, the program for children with disabilities received authority under the *Child Welfare Act* (Government of Alberta, 2019). During the *Child Welfare Act* review, caregivers and stakeholders explained how the unique needs of children with

Figure 1. Navigating the Children's Disability System in Manitoba



disabilities and their families were not being met (Government of Alberta, 2019). This Act governs Alberta's Family Support for Children with Disabilities (FSCD) Program which promotes family-centred practice, and administers services, including basic needs, counselling, temporary out-of-home placements, case management and coordination, and respite for children with disabilities (Government of Alberta, n.d.-a). Children with "severe disabilities" are eligible for specialized services, which include an interdisciplinary team (Government of Alberta, n.d.-b).

What are the Rights of Children with Disabilities?

Not everyone starts from the same position in life. This makes it more difficult for some individuals or groups of individuals to realize their rights and grow into their unique potential, including children with disabilities. Treating everyone the same only leads to equality if everyone starts from the same position and is given the same opportunities in life.

Substantive Equality

Substantive equality is a legal principle in Canada that requires "recognizing and responding to difference and remedying discrimination and stereotyping" (Vandervelde v. Goodlife Fitness Centres Inc., 2012). Substantive equality seeks to correct the inequalities vulnerable people in the community experience, with the goal of ensuring that the outcomes or results for all people are equal, which may require special accommodation (Kanter, 2015).

For children living with disabilities, substantive equality may mean accessing additional resources and services they need for getting an education (transportation to school, implementing Individual Education Plans), communicating (tablets, speech pathology, sign language), or for mobility (wheelchairs and other mobility devices).

"I have a very expensive child, I know this! But she is a person, she has rights. I want people to see the value in my child."

– Caregiver Interview

Resource Allocation

Without additional resources and supports, children living with disabilities are not able to realize their inherent rights, including the right to education, employment, and family relationships. Article 4 of the UNCRC states that in order to realize the rights of children, governments should undertake all appropriate legislative, administrative, and other measures "to the maximum extent of their available resources." This article commits governments to centre and prioritize the human rights of children when making decisions about resource allocation.

In a General Comment on children with disabilities, the Committee on the Rights of Children remarked:

> The implementation of this right [Article 4, UNCRC] has been a concern to the Committee since many State parties not only do not allocate sufficient resources but

> have also reduced the budget allocated to children over the years. This trend has many serious implications especially for children with disabilities who often rank quite low, or even not at all, on priority lists...Decentralization and privatization of services are now means of economic reform. However, it should not be forgotten that it is the State Party's ultimate responsibility to oversee that adequate funds are allocated to children with disabilities along with strict guidelines for service delivery (CRC/C/GC/9, 2007).

Effective investments in resources and services for children living with disabilities are requirements of an equal and just society and the responsibility of governments.

Jordan's Principle

Ensuring non-discrimination is a **legal obligation** of the Government of Canada (Canadian Human Rights Act, 1985). The primary source of equality rights is derived from Section 15 of the *Canadian Charter of Rights and Freedoms*. Canadian jurisprudence has determined that Section 15 is not a general guarantee of equality; rather, it is a guarantee of non-discrimination.

Canadian law has reinforced the principle of **substantive equality** numerous times but the Canadian Human Rights Tribunal's decision in the case of Jordan River Anderson is the most impactful because it established Jordan's Principle as law in Canada. This law requires that the federal and provincial governments provide services to First Nations children without delay and without discrimination due to their First Nations ancestry.

Jordan’s Story

Jordan River Anderson was a boy from Norway House Cree Nation in Manitoba. Jordan was born with complex medical needs and stayed in the hospital from the time he was born until he died at five years old. When Jordan was two years old, doctors said he could move to a special home for his medical needs. The federal and provincial governments, however, argued over who should pay for his home-based care. In the end, Jordan stayed in the hospital until his death (First Nations Child and Family Caring Society, 2021).

Jordan’s Principle is “a legal requirement resulting from the Orders of the Canadian Human Rights Tribunal (CHRT) and is not a policy or program” (Assembly of First Nations, 2019). The principle is a child-first principle named in memory of Jordan River Anderson. Jordan’s Principle aims to make sure First Nations children can access all public services taking into account substantive equality, distinct cultural needs, and historical disadvantages linked to colonization, without experiencing any service denials, delays, or disruptions because of their First Nations ancestry (First Nations Child and Family Caring Society, 2021).

Per the CHRT decision, Jordan’s Principle:

- Applies to all First Nations children, regardless of whether they live on- or off-reserve.
- Applies to all government services for First Nations children, such as mental health, special education, dental, early childhood services, physical therapy, speech therapy, medical equipment, and more.
- Is not limited to children with disabilities.
- Ensures service provision to First Nations children even if the service is not available to other children.
- Ensures that Canada must decide on individual requests for supports and services for First Nations children within 12-48 hours of receiving a completed request, with special provisions for urgent cases where a child has a health or safety risk, which will be responded to within 12 hours of receiving a completed request.
- States that the government of first contact must pay for the services. Governments and departments will work together to figure out who pays afterwards.
- Applies to requests for an individual child’s needs, or those for groups of children.
- Covers diverse services. As such, any government-provided service available to all other children is included in Jordan’s Principle coverage (Assembly of First Nations, 2019).

Section 3: Methods

This section describes the combination of investigative and research methods employed in this special report. A more detailed description of the methods can be found in Appendix C of the Online Supplement.

The Child

This report began with the story of a child. By law, the Advocate receives a notification of the death of every child and youth under the age of 21 years old in Manitoba. In 2017, the Advocate received notification of the accidental death of a child with disabilities, who we are calling Emma. Our review of the death uncovered key service gaps in case management, respite, alternative care, and child welfare involvement for children with disabilities.

The System

To better understand the extent and impact of service gaps, data were requested from Children’s disAbility Services (CdS) for the five-year period between 2015-16 and 2019-20. To understand the overlap between the children's disabilities and child welfare systems, the CdS and CFS databases were linked. A review of legislation, policies, and procedures, as well as best practices was then conducted and integrated throughout this report.

The Caregivers, Children, and Youth

The perspectives of parents and caregivers are critical. Following consultations with community stakeholders, a caregiver survey was launched publicly in English and French in October 2020 and was open for a month. A total of 334 caregivers responded from across Manitoba. Further, five in-depth interviews took place with children and youth with disabilities.

The Service Providers

Current and former service providers participated in comprehensive semi-structured in-depth interviews. Through snowball sampling, a total of 21 service providers were interviewed virtually. Interviews focused on the challenges and gaps in the system, as well as opportunities for improvement.

Consultations

In order to inform recommendations, a number of roundtable consultations took place in February 2020. These began with a meeting with the Elder's Council at the Manitoba Advocate. The Manitoba Advocate also met with leadership from the public bodies reviewed in this report, including the Department of Families. In recognition of the rights of Indigenous peoples, preliminary findings were presented to First Nations and Metis governments. Later, the Advocate conducted a roundtable with approximately 20 caregivers. Lastly, an expert consultant offered feedback on an earlier version of this report. These consultations, together with the report findings, informed the recommendations.

Limitation

CdS does not systematically collect information that would allow us to understand the effects of intersectionality in the lives of the families and children they serve, including those of First Nation, Metis, or Inuit ancestry. This gap in information prevents us from having a full understanding of the structural inequalities in Manitoba's disabilities systems in the detail this deserves. A procedure dated May 6, 2020, indicated that CdS is now recording children with "registered Indian status [but]…As non-registered First Nations, Metis and Inuit children do not have treaty status, they should not be recorded on inFACT as status First Nations. However, staff should be aware of their Indigenous heritage of participants to provide culturally appropriate support" (Circular Number: CDS #2020-10).

We address the shortcomings of this policy in recommendation six*.* Understanding of the experiences of First Nations, Metis, and Inuit children with disabilities and their caregivers is essential. Where available, we have included information from the caregiver survey and internal data.

Section 4: Emma’s Story

Emma (not her real name) was a young girl of non-Indigenous ancestry, who lived in rural Manitoba for most of her childhood. She brought joy to those who knew her.

Emma was a teenager when she died accidentally. Her family had been involved with the child welfare system through a voluntary family services file at the time of her death. Emma’s circumstances met the criteria for an investigation by the Manitoba Advocate. This section provides an outline of key events in Emma’s life and a summary of government systems involvement.

Summary of Significant Events

Early years

- **Children's disABILITY Services (CdS):** referred shortly after birth, Emma's family begins to receive respite supports four hours per week
- **Emma starts daycare**
- **Child and Family Services:** first contact with child welfare to resolve a dispute with CdS regarding respite increases and access to childcare
- **Education:** starts school, school develops plan and coordinates services
- **Emma learns to walk**

Middle years

- Emma's health and behaviours become more complex, with frequent falls and injuries
- **Education:** safety concerns and injuries are reported which triggered a systems meeting
- **Systems Meeting:** systems coordinate services due to increased safety issues
- **Children's disABILITY Services:** increased respite and internal jurisdictional disputes to fund safety equipment in Emma's room

Teen years

- **Family appeals for help to the Minister of Health, "she needs care 24/7"**
- **Health:** her health deteriorates further
- **Children's disABILITY Services:** respite continues to increase, family requests referral to St. Amant, family reports that the respite worker is overwhelmed and might be experiencing "burn out"
- **St. Amant**: No placements are available for the child, St. Amant conducts an assessment
- **Education:** Educational Assistants no longer felt comfortable providing care due to increased health needs
- **Child and Family Services:** CdS meets with CFS to plan for the family, CFS does not have an adequate placement for Emma, CFS does not license new placement, jurisdictional issues with CdS occur, Level 5 placement application was submitted, preparations were made for her entry into care
- **Family appeals for help to the Minister of Families**
- **Family is in crisis**
- **Emma dies accidentally**

Section 4: Emma's Story

Summary of Government Systems Involvement

Emma's First Year

Emma was born with a form of brain damage. As a result, Emma also experienced seizures and was diagnosed with a global developmental delay which threatened her life. With supports, she was able to go home with her parents less than a month after she was born.

As she aged, Emma's seizures continued and she was diagnosed with a significant number of additional disabilities. Emma also developed sleep challenges and behavioural issues.

Many professionals were involved in providing care to Emma throughout her life. Her team included, but was not limited to, a neurologist, a psychiatrist, clinical and other nursing staff (who created health care plans to guide Emma's caregivers in her medical care), as well as a physiotherapist (PT), occupational therapist (OT), and speech language pathologist (SLP).

Emma's family was referred to the Children's Special Services (now Children's disABILITY Services (CdS) Program) when she was about one month old. CdS file documentation indicated the family's needs and a plan for those needs was discussed at that time. CdS referred the family to the Child Development Clinic where Emma received child development services and her parents received training in child development activities that could be undertaken at home to support Emma's developmental progress. As well, a Family Service Worker (FSW) from CdS was assigned to work with the family and asked them to complete a Family Needs Survey in order to better understand the family's priorities. The survey indicated that the family wanted information on how children grow and develop, how to play with, talk with, and teach Emma, and information on the services that could be made available for Emma, including respite.

Respite Services Begin

Following discussions regarding the family's priorities, the FSW and Emma's family completed an agreement for self-administered respite that provided them with three hours of respite per week. A contract for a respite worker through CdS was also signed, which provided the family with an additional three hours of biweekly respite support. Furthermore, a child development worker, a PT, OT, and SLP also began working with Emma and her family in the first year of her life.

Start of Daycare

When she was one, Emma began attending a daycare most week days. Service providers involved with Emma, including her PT and OT, delivered therapeutic interventions at her family home and daycare. Service provider records indicated the daycare provider's use of therapeutic techniques was helping Emma develop gross and fine motor skills.

Once Emma's sibling was born, the family appeared to be under increasing stress as the parents cared for their two young children. Emma was noted to have tantrums for hours at a time and had a hard time sleeping. While the family had access to respite support at the time, they indicated they needed more respite from CdS. The family's support network – including her pediatrician and extended family – advocated to CdS on the family's behalf.

Two years after the birth of her sibling, Emma's family received more respite support. The family received a new contract for self-administered respite and an additional contract for the provision of overnight respite two nights per week.

Removal of Daycare Supports

When Emma turned four, the family requested CdS approval to have Emma attend daycare five days per week. This request was due, in part, to the birth of the family's third child and because Emma's mother indicated she was struggling to cope with Emma's growing needs and those of her two younger children.

Documentation indicated the CdS worker, childcare coordinator, and the child development worker felt Emma was not happy at the daycare she had been attending the three previous years, noting "it is in [Emma's] best interest for her to be at home. She is much more settled at home." Available documentation indicated this opinion was shared by other service providers, but does not state how this conclusion was arrived at or if this rationale was communicated to the family.

The following month, CdS denied the family's request for additional daycare supports and indicated daycare supports would be removed altogether because Emma's mother was on maternity leave and was no longer "eligible for any daycare supports." Instead, CdS offered the family four hours of in-home respite support daily and afternoons at the daycare to "wean the family from daycare." A meeting with the family occurred. At this time, CdS identified Emma's final day at daycare and also spoke of involving Child and Family Services (CFS) in Emma's care.

First Involvement with Child and Family Services

The next day, Emma's mother and daycare provider contacted CFS requesting advocacy assistance with CdS. The CFS worker contacted the Acting Director of CdS by telephone and during the call, the Acting Director of CdS clarified that removing daycare support for parents on parental leave "is not policy that is an inaccurate and non-supportable explanation that the family cannot have daycare." It was further noted that the CdS decision to terminate daycare could be appealed.

Restoration of Daycare Supports

The family received written correspondence from CdS later that month indicating daycare would continue full-time Monday through Thursday, and four hours of in-home agency provided respite would be allotted on Fridays. The letter specifically indicated respite and therapeutic supports were to occur in-home only. This stipulation led to a disruption in the therapeutic services Emma needed for her continued development because the available timeframe to work with Emma was limited to one specific day of the week. The child welfare agency had no further recorded involvement with the family until the year Emma died.

Early Elementary School Years

Start of Kindergarten

From early on in her life, Emma worked with PT, OT, and SLP funded by CdS and provided through her Regional Health Authority's Rehabilitation Services program. As with all children with disabilities entering school, the provision of clinical (PT, OT, and SLP) and other supports transitioned to service delivery from the school division.

Starting school can be a difficult transition for many children with disabilities and their families. This challenge is often mediated through intake meetings that are held prior to school entry. These meetings involve representatives from those programs that have been supporting the child and can include clinicians (PT, OT, and SLP), child development workers, CdS workers, and school staff. Emma's family participated in an intake meeting and a plan was developed to address Emma's need for specialized equipment and transportation to and from school.

In addition, an Individualized Education Plan (IEP) was prepared which identified goals and performance objectives for Emma's continued development of gross and fine motor skills, verbal and social communication skills, and cognitive development. Based on the strengths and needs identified in Emma's IEP, the school division applied for and received approval for Level 3 funding from the Department of Education. Level 3 funding is the highest level of support possible through the Manitoba education system. Documentation from CdS and the school noted limited involvement from CdS during collaborative planning among service providers occurred. School documentation noted the importance of Emma's inclusion with her classmates and prioritized Emma's time with peers.

Furthermore, the school submitted a request to the Unified Referral and Intake System (URIS) to address Emma's health and safety needs. A registered nurse met with Emma, her family, and the school team to assess Emma and develop an Individual Health Care Plan (IHCP). The nurse subsequently provided training to the educational assistants (EAs) supporting Emma so they were able to address her health care needs at school.

Health Deteriorates

Emma began to experience seizures again around the time she began school. CdS documentation further noted the family had exceeded their yearly allocation of respite. There was no indication regarding how CdS planned to support the family during this time. Around the same time her seizures returned, Emma was noted to wake multiple times a night. She was also having difficulties eating, which resulted in her receiving a gastrostomy tube (known as a G-tube). Due to Emma's high needs, her family hired a privately paid care provider to help care for Emma in their home.

Middle School Years

Safety Concerns and Injuries

Towards the end of Grade 6, Emma began to have seizures more frequently, resulting in falls. The school also reported there were times when she appeared weak and tired. Her schedule was altered to accommodate when she needed to rest and recuperate. At home, Emma and her family continued to receive support from a privately paid care provider. A new self-administered respite agreement was also in place, which provided the family with continued respite care.

Emma's parents and her school support team maintained a seizure record as required by the IHCP. Emma's records indicated that her seizures were increasing in frequency. She was also noted to experience "startles" – described as incidents that startled and subsequently tired Emma, but did not trigger seizures. These startles and seizures were becoming a safety issue for Emma.

Systems Meeting

Because of these new developments, Emma's support team – consisting of her parents and numerous professional supports, including CdS, PT, OT, and the Disability and Health Supports Unit (DHSU) – met at the family's home to discuss new safety concerns and develop a plan for next steps. Emma had been punching and kicking holes in the walls, falling and injuring herself, banging on windows in the home, among other concerns.

Although Emma's team agreed on a plan at the meeting to make her room a place where she would not be able to injure herself, DHSU later advised it would not fund the items requested because of perceived safety issues.

In June, CdS completed a Safety Assessment Form, which noted behavioural concerns with Emma, specifically, instances of physical violence and self-harm. Subsequently, a safety plan was completed. The safety plan noted a psychological referral was submitted for Emma. Arrangements were made over the next few months for the psychologist to meet with the family for a consult regarding behavioural issues, service planning, and funding for Emma's sensory and safety needs. The psychologist was among at least three service providers involved with Emma to provide advocacy for funding needed to make safety modifications to her bedroom.

Respite Increases

According to CdS documentation, respite supports increased to 20 hours every week over the summer when Emma was not quite a teenager. A new respite worker was introduced to the family by CdS and began working with Emma on a regular basis.

The family, however, continued to struggle and required extra support. Emma's increased seizure activity, sleeping issues, and self-injurious behaviour were taking a toll on the family's emotional health. Due to an incident where Emma injured herself, Emma's mother contacted CdS that August and respite support for the family was further increased.

Six months after the systems meeting, CdS agreed to fund some of the safety equipment that had been identified for Emma's bedroom. DHSU provided funding for the additional safety equipment 18 months after the meeting occurred and following advocacy from several of Emma's professional supports. A number of internal emails between CdS and DHSU indicated that jurisdictional disputes and procedural disagreements had delayed the provision of padded flooring for Emma. An email authored by DHSU specifically referenced the "need to save money."

The Teen Years

Health Deteriorates

Emma's poor health, increasing seizure activity, sleeping and behavioural challenges continued to be an issue throughout the school year.

Family Appeals for Support

Emma's parents expressed wanting to find ways to keep their daughter in the family home as long as possible. They emailed a letter to the Minister of Health, indicating the in-home supports Emma received helped, but were not enough. They stressed that "she needs care 24/7." The family's plea to the Minister was directed to CdS' attention the following month.

Respite Increases Again

CdS and the family signed a new self-administered respite agreement the next month that included an increase in funding, covering the full cost of the family's privately paid care provider. The family had been privately funding the care provider for almost eight years at this point.

Emma's Last Year

Need for Alternative Care

The family began exploring long-term care options for Emma that spring, contacting St. Amant in Winnipeg (a drive of several hours from the family home). Emma's mother explained to the CdS worker in an email, "We love her and would love to keep her either in our home or at least near to us, but if this is not an option we have to start considering other options."

Referral to St. Amant

In early summer, Emma's CdS worker sent a referral to St. Amant's attention, requesting an out-of-home placement for crisis stabilization. This would allow for a medical assessment and review until an appropriate long-term resource was identified or developed for Emma. This referral was made more than two months after the family began discussing long-term care for Emma with CdS. Alternative out-of-home care options are extremely scarce in Manitoba. According to the St. Amant referral form, admittance to St. Amant could take up to two years for children who are assessed as a priority.

At the same time, internal planning at CdS was occurring about transitioning Emma into adulthood. CdS documentation indicated, ideally, planning would involve having CFS provide a foster home or group care license since CFS (not CdS) had the legislative ability to license and fund such placements.

Issues with School and Respite Supports

Before the end of the school year, a meeting was held between CdS, school representatives, and Emma's parents. The school discussed some of its concerns respecting Emma's deteriorating health and behaviour. It was further documented that Emma's EAs felt Emma's needs had exceeded their abilities and they no longer felt capable of meeting her needs.

Second Child Welfare Involvement

The same day, with the family's permission, CdS met with CFS to discuss long-term planning. CdS reported the family was struggling to manage, and there was a possibility Emma may enter CFS care in a crisis. A voluntary family services file with the family and CFS was opened.

No Out-of-home Placements and Respite Burn-out

CdS and St. Amant communicated about Emma's referral during the summer. St. Amant advised there was no residential placement availability and indicated the referral would be considered on a monthly basis, or as space became available. St. Amant suggested CdS check back after the summer.

Over the summer, CdS documentation indicated that an incident with Emma's respite worker occurred. When CdS checked in with the respite worker, they denied feeling overwhelmed. Nonetheless, CdS amended the exisitng safety plan in response to this incident. The plan noted consultation with a behaviour psychologist through the Department of Families was to occur regarding safety planning specific to Emma's care and care providers' interactions with her. Details regarding whether this consultation occurred were not documented in the information provided during this investigation. CdS also planned to enroll the respite worker in non-violent crisis intervention training, a request that had been previously refused when the respite worker had made an enquiry about it.

A few days later, the CFS worker met with Emma's parents and CdS to discuss what had been going on with Emma. CdS advised it was exploring Manitoba Developmental Centre – a residential facility for adults – due to a lack of available placement resources that could meet Emma's needs. Given the lack of resources in Manitoba, service providers briefly broached the idea of an out-of-province placement, something Emma's family immediately indicated would not be an option for their child; they wanted Emma to live as close to the family home as possible.

Emma's family enquired about CFS placements designed for children with complex needs in Manitoba. The CFS worker contacted agency management after the meeting to ask about what types of placements could be available to Emma. By the end of the month, CFS documentation indicated the worker had been advised there were no placements available to the CFS agency that could meet Emma's complex needs.

In late summer, CFS learned of a potential placement and applied for it through the Provincial Placement Desk (PPD). Although CFS and St. Amant were in the process of licensing a new home, this was not deemed a suitable fit for Emma, as the care provider for the home did not have adequate experience. The lack of a placement to meet Emma's care needs continued to be an issue.

A Family in Crisis

In early fall, service provider documentation noted the family was in crisis. The family did not believe service providers understood things were "…NOT good." The CdS worker reached out to CdS management

explaining, "the home situation is rapidly deteriorating… [Emma] needs to be out of home now…if we aren't able to take action soon this will become a protection issue for this family."

It had been six months since the family began discussions with CdS about out-of-home care for Emma. Service provider documentation from the various stakeholders described that Emma's parents were losing patience over this lengthy process and were now in the midst of a crisis due to the lack of an appropriate placement to meet Emma's care needs.

Jurisdictional Disputes between CdS and CFS

Jurisdictional disputes between CdS and CFS remained an issue that fall, when the organizations continued to be unsuccessful in locating or developing an out-of-home placement for Emma. Emails among the organizations were exchanged, with CFS identifying it was not in agreement about taking Emma into care, stating, "the system's inability to meet the increasing family needs is what is creating the crisis…child welfare has no capacity to meet her specialized needs, which is your programs' expertise." CdS countered, saying it had "no authority or legislation to provide anything more than temporary parenting relief." Disputes between the organizations continued, as noted in service provider documentation. CFS encouraged Emma's family to "call the minister," while CdS responded by stating "current legislation prevents CdS from licensing resources or placing children, which is a CFS mandate." Eventually, Emma's family contacted the Minister of Families requesting assistance in securing a placement at St. Amant for their daughter.

The leadership of the General Child and Family Services Authority subsequently reached out to St. Amant leadership about Emma's referral. Following this conversation, St. Amant documentation noted coordinators for nursing, psychology, and social work had been asked to prioritize completing a needs assessment for Emma, which was completed shortly thereafter. Service provider documentation indicated the Child and Family Services Division advised the CFS agency it would not be approving any proposals to create new, staffed placement resources. Documentation from CFS explains:

> Our reluctance to try and create a resource for [Emma] is for two main reasons:
> We have little capacity to take on creating a new resource for [Emma]. We are barely able to keep our staffing levels at our current group care/staffed programs at sufficient levels. We do not have the expertise of looking after a child with such significant medical needs. Further, we have been advised by the Division that it will not be approving any proposals to create new staffed facility programs…As a result, we are turning back to the system through the PPD [Provincial Placement Desk] to locate a suitable program for [Emma], thus the call for a systems/resource planning meeting.

This meant Emma's support team would be relying on the placement application sent by CFS to the PPD the previous month. PPD, however, had already determined there were no placements available that could meet her needs and discussed developing a placement through an outside resource. A meeting between service providers was scheduled to discuss matters further. "A team meeting was held with CFS and CdS and it appeared as though [Emma] would likely be entering care due to the fact there were no alternatives for [Emma]." The lack of suitable out-of-home alternative care placements left the family without any options for supports outside of the child welfare system.

Emma's mother contacted our office, the Manitoba Advocate for Children and Youth, in the weeks before Emma's death to express her frustration regarding how long it was taking to find an appropriate placement for her daughter. At that time, the mandate of our office did not include disability services. MACY's involvement, due to the then-limited mandate, focused on the CFS involvement and after a review of CFS service provision, identified that the child welfare system was working with CdS to locate a placement for Emma. Our office recommended that Emma's family contact the Manitoba Ombudsman (which did have formal jurisdiction at that time) and St. Amant management.

The Manitoba Advocate's mandate expanded to include disability services and several other service areas just months after Emma's death.

Circumstances Surrounding and Following Emma's Death

That fall, Emma died in an accident. Shortly after her death, her friends and family gathered for a celebration of life in her honour.

CdS completed a brief internal review surrounding the specific circumstances of her death. Shortly after her death, Emma's CFS Authority contacted the CFS Division to enquire about the status of a recommendation that the Manitoba Advocate (then Children's Advocate) made in 2016, concerning a protocol to enhance collaboration between CFS and CdS. If implemented, the recommendation may have prevented some of the jurisdictional disputes that occurred in the last year of Emma's life. At the time of Emma's death, no such protocol was in effect.

Investigation Themes and Findings

Through the investigative process, the following key themes were identified:

Case Management from CdS

Finding 1: While there was a great deal of time and effort spent attempting to secure a long-term placement for Emma, CdS did not conduct regular, formal needs assessments of Emma and her family. Internal policies require the development of annual plans. Instead, CdS relied on the family or other systems to communicate changing needs and advocate for themselves prior to creating a plan or coordinating services.

Respite Services

Finding 2: Throughout their involvement with CdS, Emma's family struggled to get the amount and type of respite services they believed they needed. The family sometimes resorted to contacting provincial ministers, getting letters of support from family and medical professionals, and appealing to other systems to advocate for respite services.

Finding 3: Self-administered respite placed added responsibilities on the family, such as the employment of respite personnel and overseeing all aspects of service delivery, including identifying respite worker burn-out.

Alternative Care

Finding 4: Gaps in the availability of short- and long-term out-of-home placements (including crisis stabilization) in the community created added stress, and led to the involvement of CFS in the care and planning for the family.

Jurisdictional Issues between CdS and CFS

Finding 5: CdS does not have a legislative mandate. The program cannot create, license, staff, fund, or oversee out-of-home placements for children with disabilities and their families. CdS therefore involved CFS in planning an out-of-home placement for Emma.

Finding 6: In the months before her death, CdS and CFS were unable to coordinate services to provide Emma with the long-term out-of-home placement she needed to address her high needs.

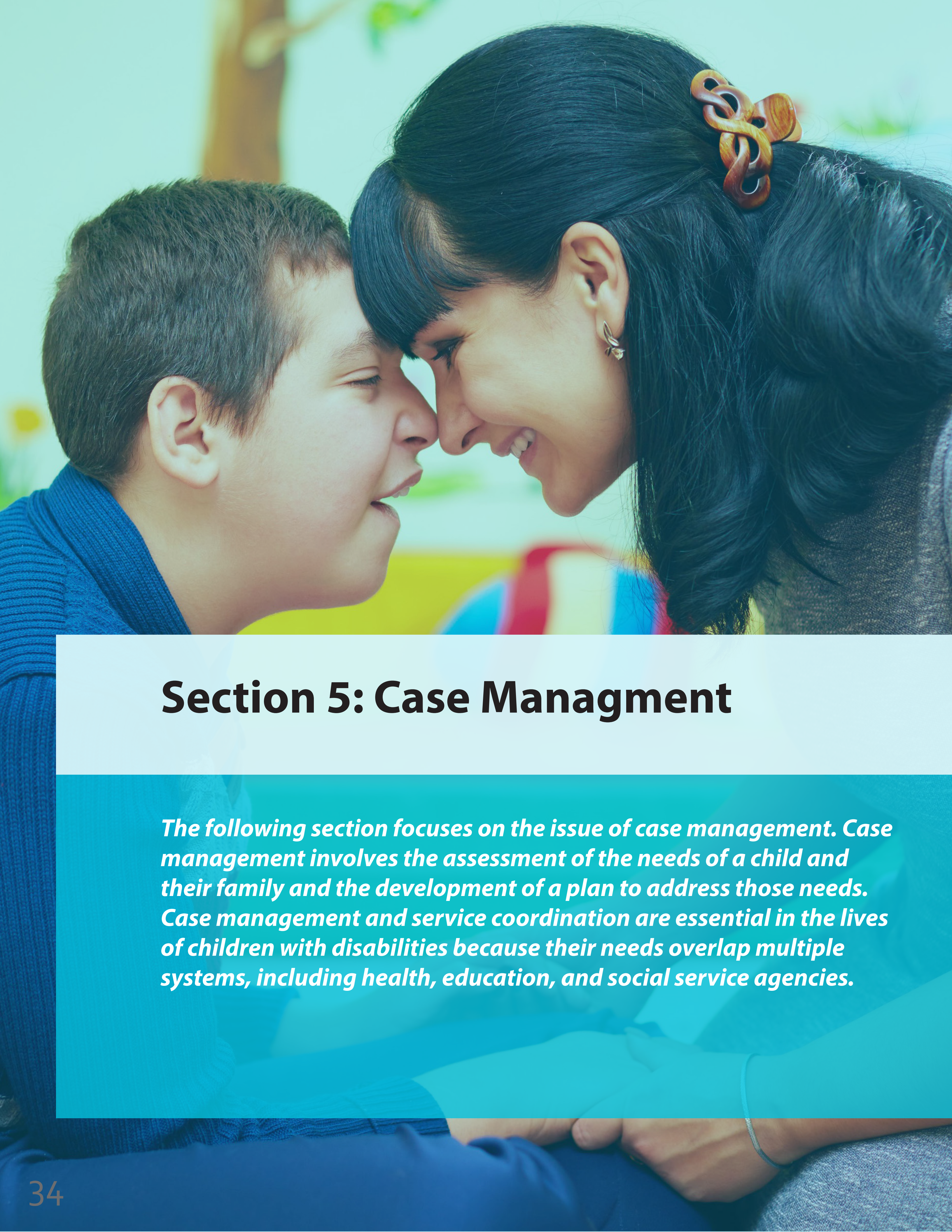
School Supports

Finding 7: School supports throughout Emma's life were consistent with the rights of children with disabilities to live with dignity, access education, and participate in society. The school created yearly plans and coordinated school-based services appropriately.

We recognize that while school-based services provided to Emma and her family were consistent with the principles of the CRPD, this is not always the case. A recent report by the Canadian Human Rights Commission details the challenges and barriers faced by youth with mental or physical disabilities when accessing Canada's education system (Canadian Human Rights Commission, 2017). In fact, the caregivers that answered our survey discussed serious concerns with the ability of children with disabilities to realize their right to education. While this issue falls outside the focus of this report, it continues to be monitored by the Manitoba Advocate.

Conclusion

The themes and issues identified through Emma's investigation highlight systemic and substantive equality issues that required further examination, including: (1) case management services; (2) respite services; (3) access to alternative care; and (4) the overlap with child welfare services. The extent and nature of these issues are considered in detail in the following sections of this special report through analyses of administrative data, caregiver survey data, key informant interviews, reviews of policies, and an exploration of best practices.



Section 5: Case Managment

The following section focuses on the issue of case management. Case management involves the assessment of the needs of a child and their family and the development of a plan to address those needs. Case management and service coordination are essential in the lives of children with disabilities because their needs overlap multiple systems, including health, education, and social service agencies.

Section 5: Case Management

Key Findings

- Children's disABILITY Services (CdS) is guided by the family-centred model, a best practice.
- Wait-times of 12 to 14 months for diagnostic assessments compounded with wait-times in CdS case manager assignments, delay access to early interventions for children. Indigenous caregivers were more likely than non-Indigenous caregivers to report challenges in obtaining a diagnosis for their child (45.8% vs. 32.4%).
- While approximately 90% of children referred to CdS were accepted, older children and children involved with CFS were more likely to be deemed ineligible for services.
- High caseloads for CdS workers make it difficult for case managers to meet the principles of family-centred care and the case management service standards set out by CdS.

Children's Rights

Determining what a child with a disability and their family need through careful assessment and then developing a plan to meet those needs is instrumental for ensuring that every child receives the best possible health outcomes – as is their right (Article 4, UNCRC). Children with disabilities also have the right to be actively involved in the decision-making processes concerning the services to which they are entitled (Article 4.i.3, CRPD). It is the responsibility of governments to recognize these rights, and to encourage and ensure assistance to children with disabilities and those responsible for their care (Article 23.2, UNCRC).

As noted by the United Nations Committee on the Rights of the Child, children with disabilities need multidisciplinary services and it is essential that governments set an appropriate coordinating body, supported at the highest possible level and adequately resourced, to ensure services do not become fragmented (CRC/C/GC/9, 2007).

Case Management in Manitoba

Children's disABILITY Services (CdS) – a program within the Department of Families – is the primary program that provides case management and other services for eligible children with disabilities and their families. To qualify for CdS, a child must be 18 years or younger, live with their family in Manitoba, and have a medical diagnosis of one or more of the following: intellectual disability, developmental delay, Autism Spectrum Disorder, or lifelong physical disability with significant impairments in mobility and/or a high probability of a developmental delay due to a pre-existing condition.

CdS is not a mandated (legislated) program. The CdS policy manual (2002) states services are voluntary and discretionary, which means that "eligibility for services does not confer automatic entitlement to service for children with disabilities and their families. Rather, the delivery of services and supports are subject to assessed needs, eligibility criteria, and based on available resources, regional allocations and appropriate human resources."

Definition of Family-Centred Service Delivery

The philosophical framework for case management used by CdS is the family-centred model of practice. This approach is based on the belief that the best way to meet children's needs is within their families and the most effective way to ensure safety, permanency, and well-being is to provide services in ways that engage, involve, strengthen, and support families. When we met with senior department representatives, they reinforced that their approach is to work alongside families who are accessing disability services, recognizing the central role of family (Senior CdS staff, Interview, March 16, 2021). Principles of family-centred services include:

1. The family (not the professional) is the constant in the child's life and holds essential child expertise and knowledge to inform service planning and delivery;
2. Families are best positioned to determine what is best for the well-being of the child because they are the experts on the child's abilities/needs;
3. Children's well-being and development depend on the well-being of all other family members and of the family as a whole. Children are best helped when family needs are considered and addressed; and,
4. Families work together with service providers to make informed decisions – based on the strengths and needs of all family members (including the child) – about what services and supports the child and family receive (Dempsey & Keen, 2008; G. King & Chiarello, 2014; Susanne King et al., 2004; Kokorelias et al., 2019; Uniacke et al., 2018).

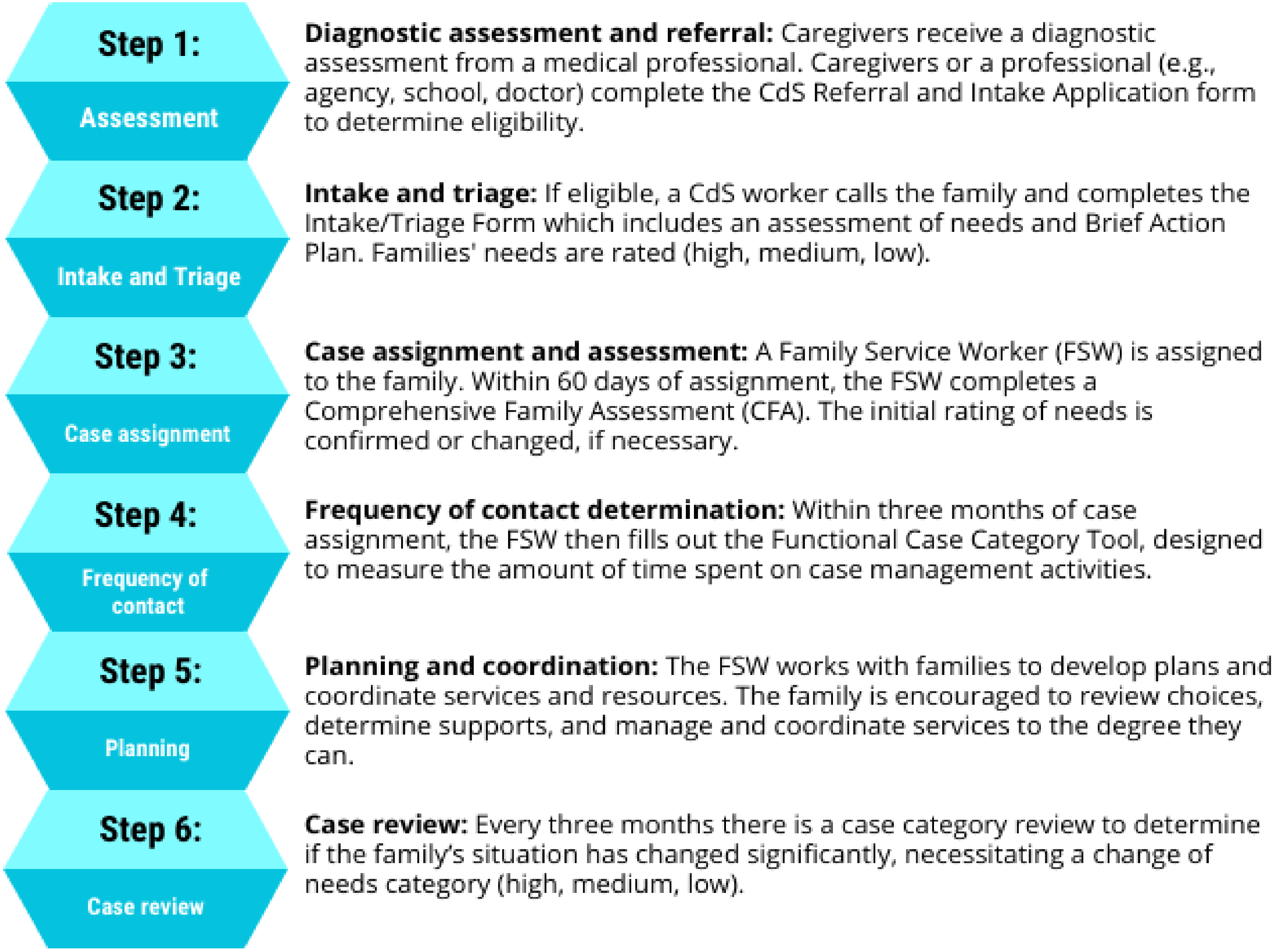
Evidence for Better Child and Family Outcomes

Family-centred service is considered a best practice and is being increasingly adopted in disability service organizations across North America (Almasri et al., 2018; Bailey et al., 1992; Baird & Peterson, 1997; Susanne King et al., 2004; van Veelen et al., 2017). The following outcomes have been attributed to the family-centred model of practice:

- Increased developmental progress, including positive educational outcomes (Barnard-Brak et al., 2017; Caro & Derevensky, 1991).
- Better psychological adjustment compared to children who received standard care (Stein, R.E. & Jessop, D.J., 1984).
- Improved behaviour for children with Autism Spectrum Disorders (Bulkeley et al., 2016; Schultz et al., 2011).
- Increased psychological well-being, including less perceived stress, anxiety, and overall better psychological well-being for mothers (Banerjee et al., 2018; Brinker et al., 1994; Case-Smith, 2013; Coogle & Hanline, 2016; Ireys et al., 2001; Susanne King et al., 2004; McAllister et al., 2018; Miller et al., 1992; Muthukaruppan et al., 2020; Riper, 1999; Stein, R.E. & Jessop, D.J., 1984).
- Increased feelings of competency, empowerment, knowledge, participation in parents of children with disabilities (Dempsey et al., 2009; Fordham et al., 2012; Hielkema et al., 2020; Muthukaruppan et al., 2020), self-efficacy (Marcenko & Smith, 1992; Moxley-Haegert & Serbin, 1983), and satisfaction with services received (Trute & Hiebert-Murphy, 2007).

Children’s disABILITY Services Case Management Process

The following process summarizes the policies related to the case management process, from diagnosis to service delivery.



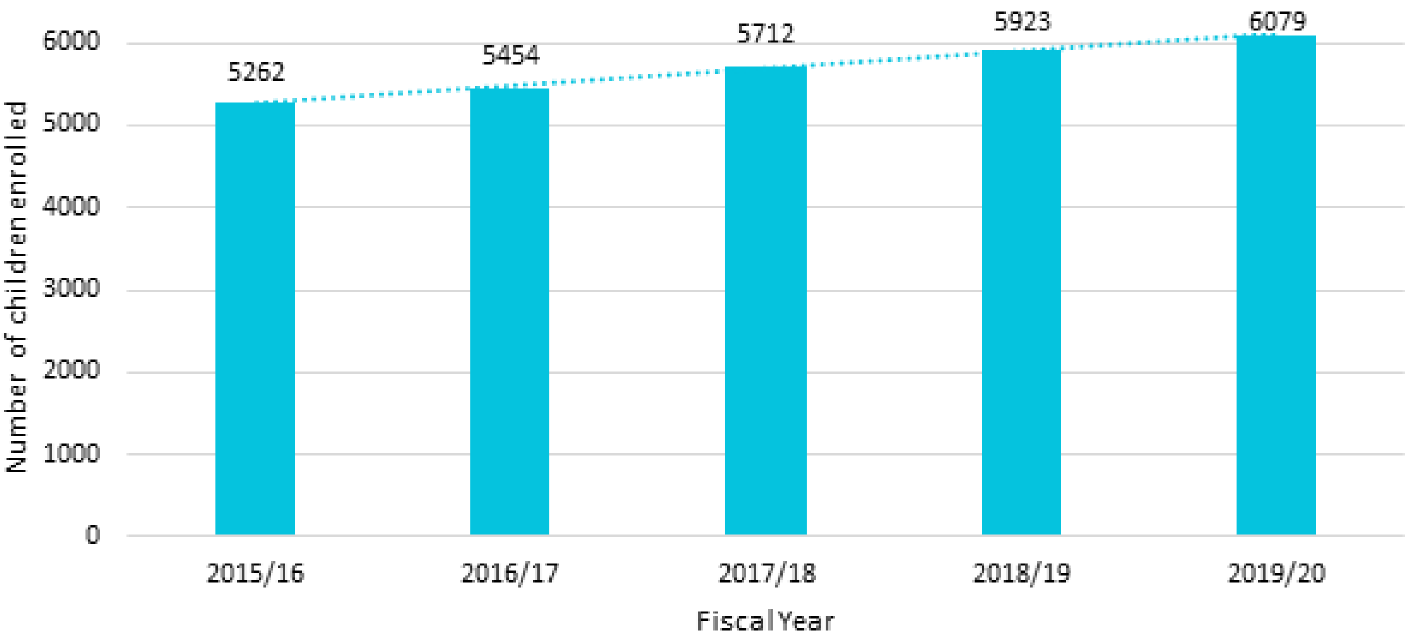
Step 1: Assessment	**Diagnostic assessment and referral:** Caregivers receive a diagnostic assessment from a medical professional. Caregivers or a professional (e.g., agency, school, doctor) complete the CdS Referral and Intake Application form to determine eligibility.
Step 2: Intake and Triage	**Intake and triage:** If eligible, a CdS worker calls the family and completes the Intake/Triage Form which includes an assessment of needs and Brief Action Plan. Families' needs are rated (high, medium, low).
Step 3: Case assignment	**Case assignment and assessment:** A Family Service Worker (FSW) is assigned to the family. Within 60 days of assignment, the FSW completes a Comprehensive Family Assessment (CFA). The initial rating of needs is confirmed or changed, if necessary.
Step 4: Frequency of contact	**Frequency of contact determination:** Within three months of case assignment, the FSW then fills out the Functional Case Category Tool, designed to measure the amount of time spent on case management activities.
Step 5: Planning	**Planning and coordination:** The FSW works with families to develop plans and coordinate services and resources. The family is encouraged to review choices, determine supports, and manage and coordinate services to the degree they can.
Step 6: Case review	**Case review:** Every three months there is a case category review to determine if the family’s situation has changed significantly, necessitating a change of needs category (high, medium, low).

Who is Accepted into CdS?

During the previous five fiscal years, 4,292 unique children were referred to CdS intake to confirm eligibility for the program, and between 735 and 872 children were accepted into CdS annually. The number of children in CdS’ provincial caseload increased by 15.5%, from 5,262 children to 6,079 children, between the 2015-16 and 2019-20 fiscal years (Figure 2).

In the last five fiscal years, approximately 90% of children referred to CdS were deemed eligible to receive service. The most common diagnosis among children who were accepted was Autism Spectrum Disorder (ASD) (41.7%) followed by developmental delay (32.6%). Children who were deemed not eligible for CdS during these five fiscal years were more likely to be older ($p < 0.001$) and involved with the child welfare system than children who were accepted ($p < 0.0001$).

Figure 2. Total Number of Children Enrolled in Children's disABILITY Services by Fiscal Year



Experiences with Case Management in Manitoba

The family-centred framework of CdS is considered best practice. Responses from caregivers in our survey, however, in addition to findings from Emma's child death investigation, suggest there are inconsistencies between policy and practice.

Diagnostic Assessment and Referral

Receiving a diagnosis is often the first condition to access many services, including CdS. The Child Development Clinic (CDC) is the largest provider of neurodevelopmental assessments (e.g., assessments for autism diagnosis) to children and youth in Manitoba before they start school. The CDC receives between 1,500 and 1,600 referrals for assessments annually (Interview with CDC, February 26, 2021). As of February 2021, the wait-time for an assessment at the CDC was between 12 and 14 months; during the COVID-19 pandemic, the waitlists increased to approximately 16 months (Interview with CDC, February 26, 2021).

“The wait times for Child Development Clinic are HORRENDOUS. 14-18 months are continually getting longer. I have watched the clinic…do everything in [its] power to shorten the wait-times but is given no resources to do it. Parents wait 18 months to get a diagnosis. Then they wait to get contacted by the intake worker, THEN they wait to hear from a case manager and THEN they wait to get picked up by the Child Development Program if that is their service of choice…they are missing kids that could use the services because they sat on the Clinic waitlist for SO long and are then too old for Early Intervention.”

– Disability Service Provider

According to analysis of administrative data completed by our office, the most common referral source for children with disabilities into CdS is the Child Development Clinic (approximately 55% each fiscal year). Many parents expressed frustration over the current delays:

“I understand we are a publically funded system, however the wait for diagnosis and then another 2+ year wait for services unless we go private is unacceptable. My son will be a pre-teen, where as if services were provided sooner, during his formative learning years they have the potential to be more impactful.”

– Caregiver Survey Respondent

Although studies have shown that timely provision of early intervention services can improve outcomes for young children with disabilities (Conroy et al., 2018; Nordhov et al., 2012), the time between referral to diagnosis in Manitoba is long and often prevents children from receiving such needed therapies (Jimenez et al., 2014; Rosenberg et al., 2013). Of note, Indigenous caregivers were more likely than non-Indigenous caregivers to report challenges in obtaining a diagnosis (45.8% vs. 32.4%).

Interviews and caregiver survey responses indicate that receiving a timely diagnosis may be a barrier for some children to access services. Receiving early intervention services is both beneficial to children with disabilities and it is their right. As stated in the CRPD, state parties must “provide those health services needed by persons with disabilities…including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children” (Article 25.b).

Case Assignment and Assessment

Analysis of case management data provided by CdS indicates that as of September 30, 2020, 393 children had been deemed eligible for the program, but were still waiting for a case manager to be assigned to them. Delays in the assignment of a case manager result in delays in accessing crucial services such as respite.

> **"I am very disappointed to be honest. We received a letter from CdS that a social worker [family service worker] would contact us in February 2019 and we have not heard anything since then at all [as of October 2020]."**
>
> – Caregiver Survey Respondent

CdS reported to Manitoba Advocate staff the waitlist for assigning CdS case management services could be up to two years (CdS personnel, Interview, June 24, 2020). In summary, the combination of delays in both receiving diagnostic assessments from the Child Development Clinic and being assigned case managers from CdS are a problem for families, ultimately resulting in delayed and in some cases denied access to crucial early intervention supports for children and families.

The Experiences of First Nations and Metis Caregivers

Once children are assigned a case manager, it is important that the families receive culturally competent care that meets the needs of families. One expert noted that:

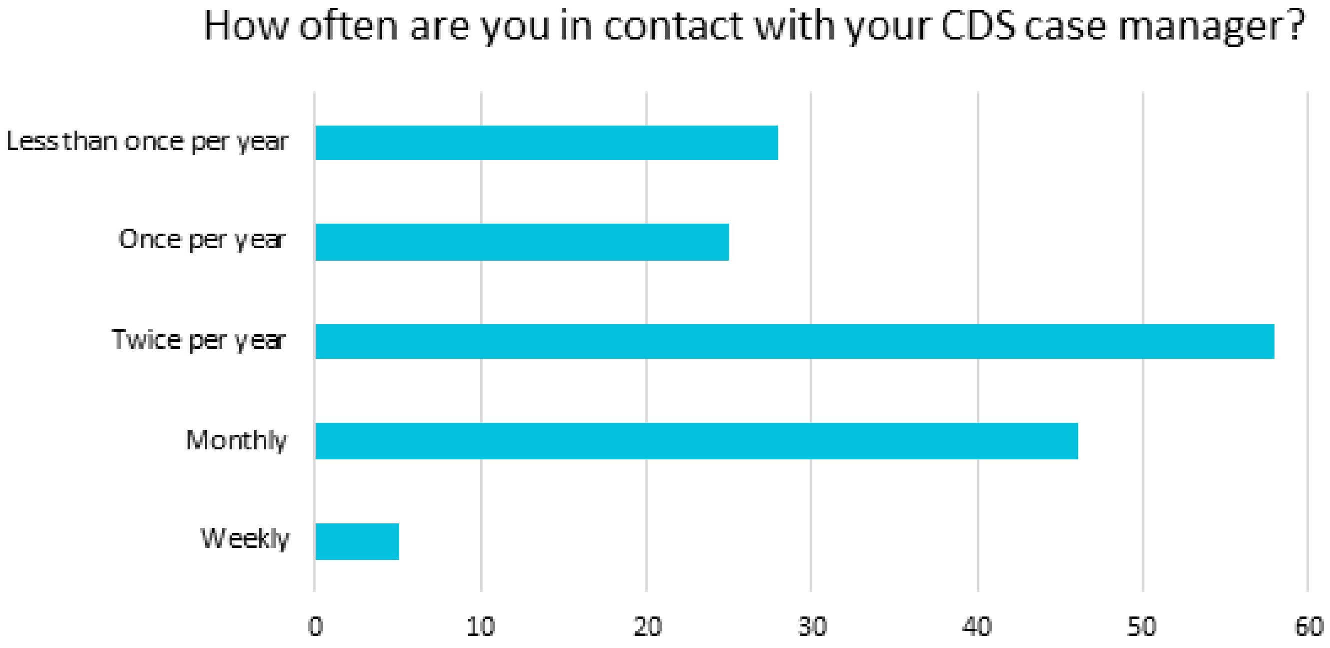
> **"Knowing the disproportionate number of kids with disabilities in Indigenous communities, there needs to be designated staff who are First Nations and Metis who have cultural competency and can understand living on reserve or inner city to help with navigation."**
>
> – Disability Systems Expert

Because Children's disABILITY Services did not systematically collect information on identity of First Nations, Metis, and Inuit children they served, we are unable to determine the number of Indigenous children served by CdS, the services they received, nor their outcomes. A new procedure was established in May 2020 indicating that CdS should now record children with "registered Indian status [but]… as non-registered First Nations, Metis and Inuit children do not have treaty status, they should not be recorded on inFACT as status First Nations. However, staff should be aware of their Indigenous heritage of participants to provide culturally appropriate support." As such, CdS policy still prevents an understanding of the unique challenges faced by First Nations, Metis, and Inuit children, regardless of their status as assigned by a colonial system. Indigenous experts shared with MACY that the CdS policy is missing many kids, and those kids deserve to be identified.

Frequency of Contact

One of the goals of CdS' case management is to ensure that "families are supported, to the extent required, in optimizing their strengths and competencies as parents, resource managers and advocates" (Children's Special Services, 2007, p. 5). Responses from the caregiver survey indicate that many families are not receiving contact from caseworkers to the extent they require. For instance, when asked to share their experiences about their child's disability case manager in an open-ended response, 31% indicated their frustration with the lack of contact from their worker.

Figure 3. Contact With Case Manager, Caregiver Survey Responses (N=161)



Of the respondents who indicated their child did have a case manager, 69% reported their case manager contacted them twice a year or less, while 28% received monthly contacts, and 3% weekly (Figure 3). One caregiver said there was "no communication unless we reach out. Last time we heard from them was October 2019 [a year prior to the survey response]. Very disappointing." A different respondent noted their worker was "hard to reach. Only communicated if we reached out first and then there was still a delay in response." What families identified in the caregiver survey is in line with CdS' current approach. A former CdS employee noted that under CdS' current case management model, which categorizes families as low, medium, or high needs, some families would not receive ongoing supports and plans if their initial assessment did not identify that they were a family with high needs.

Senior CdS staff explained the rigorous process by which case weighting was designed to maximize scarce resources based on need.

> **"Case weighting determines how much time a worker spends with a family. A family deemed not to have high needs at intake would get a phone number to call someone if they need."**
>
> – Former Disability Service Provider

Interviews with children reflected their wish to have a personal relationship with case managers and other service providers that goes beyond an assessment of their disability and centres them as a person, as the quote below indicates. Developing meaningful relationships with children and their families requires regular contact and time.

> **"Get to know the person not the disability. Understand the person not the diagnosis."**
>
> – Child Interview, age 11

Planning

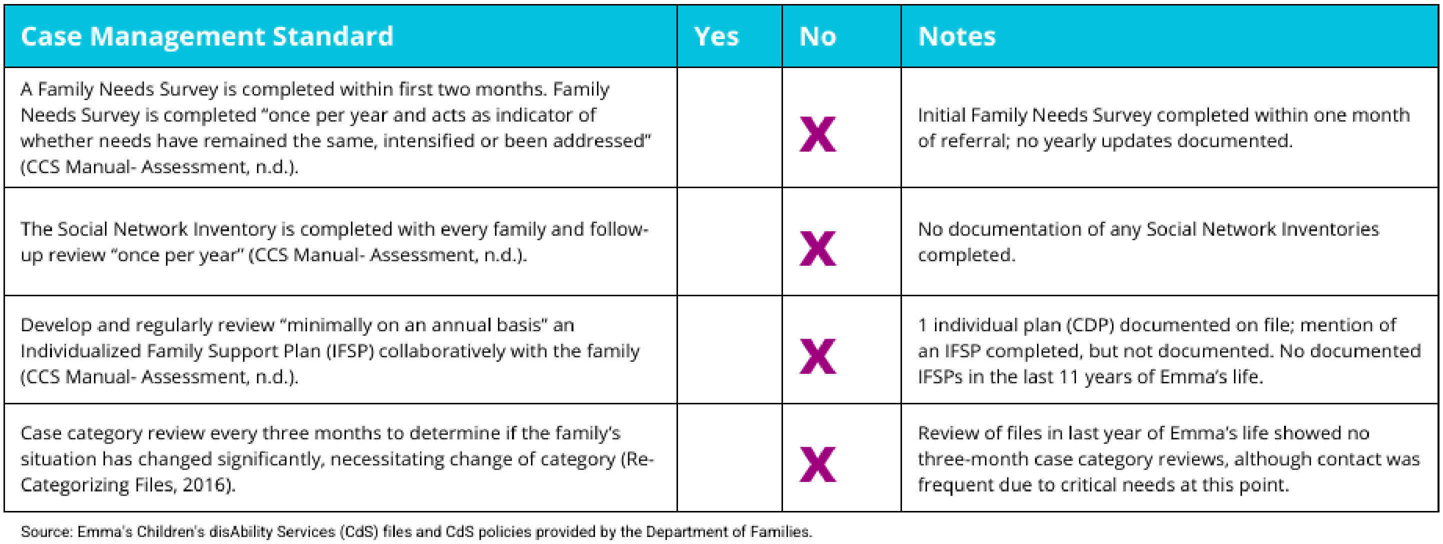
As noted above, CdS' case management protocol states that a FSW is to work with the family and complete the Comprehensive Family Assessment (CFA) within 60 days of being assigned a case (Children's Special Services, 2002). Further, CdS policy states: "Parents are partners in planning for natural supports and generic and formal resources and services that address the unique needs of the child and family" (Children's Special Services, 2002).

Responses provided by caregivers in MACY's caregiver survey and stakeholder interviews indicate that family-centred planning was uncommon. Of the caregivers who indicated their child had a case manager, almost half (48%) reported that no such plan was made by their case manager, and an additional 23% did not know or remember (see Figure 4 on page 44). For example, a respondent to MACY's caregiver survey stated, "I have never met our case worker in person and don't have any plan developed for my child and services he requires." Responses from caregivers are consistent with the experiences of Emma and her family.

Emma’s Story

- Emma was referred to Children’s Special Services (later CdS) shortly after birth and was assigned a case manager.
- Throughout her life, CdS case management relied on the family to reach out to them to access or alter supports.
- A review of the CdS file shows there were no proactive or regular assessments or plans of the child or family needs, beyond the initial assessment when Emma was an infant. Planning was conducted following a crisis (Table 1).
- The FSW advocated strongly for the family in a time of crisis and attempted, to the best of their ability, to coordinate residential care in the months prior to Emma’s death.

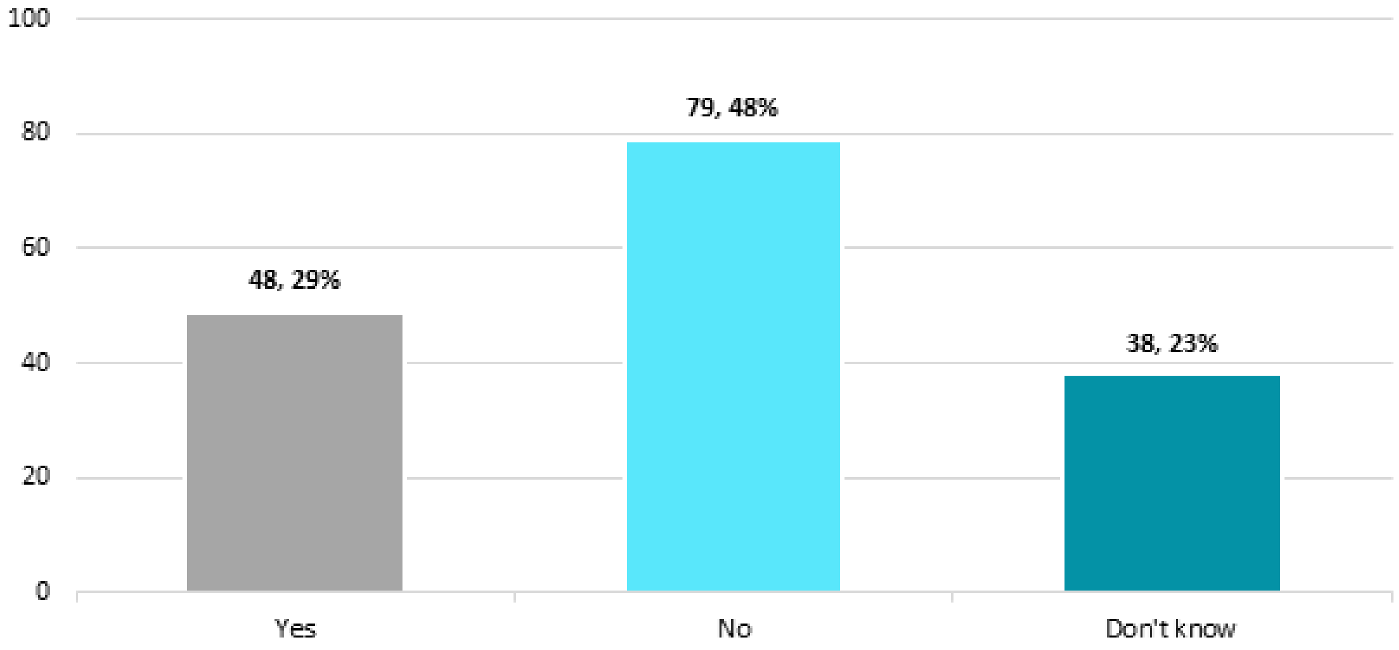
Table 1. Comparison of Case Management Standards to Emma’s Experience



Case Management Standard	Yes	No	Notes
A Family Needs Survey is completed within first two months. Family Needs Survey is completed “once per year and acts as indicator of whether needs have remained the same, intensified or been addressed” (CCS Manual- Assessment, n.d.).		X	Initial Family Needs Survey completed within one month of referral; no yearly updates documented.
The Social Network Inventory is completed with every family and follow-up review “once per year” (CCS Manual- Assessment, n.d.).		X	No documentation of any Social Network Inventories completed.
Develop and regularly review “minimally on an annual basis” an Individualized Family Support Plan (IFSP) collaboratively with the family (CCS Manual- Assessment, n.d.).		X	1 individual plan (CDP) documented on file; mention of an IFSP completed, but not documented. No documented IFSPs in the last 11 years of Emma’s life.
Case category review every three months to determine if the family’s situation has changed significantly, necessitating change of category (Re-Categorizing Files, 2016).		X	Review of files in last year of Emma’s life showed no three-month case category reviews, although contact was frequent due to critical needs at this point.

Source: Emma's Children's disAbility Services (CdS) files and CdS policies provided by the Department of Families.

Figure 4. Case Planning, Caregiver Survey Responses (N=165)



CdS policy acknowledges child and family care plans are crucial because they "reflect goals and steps to be taken to achieve family priorities" (Children's Special Services, n.d.). It is imperative, therefore, that all children receive a plan reflecting the strengths and needs of both the child and the family.

Systems Navigation

According to CdS policy and consistent with the family-centred approach, "the family is provided with the information required to enable them in making an informed choice and decision regarding the types of services to be used" (Children's Special Services, n.d.). Results of the caregiver survey suggest that many families are not receiving the information they need regarding system navigation.

When caregivers were asked what they felt were the top disability service-related challenges they faced, more than half (53%) noted having to navigate the complex disability system. This was the second most frequent challenge listed, behind only accessing services (63%). One caregiver expanded on this issue, stating, "Navigating the disability services, hospitals, doctors. Everything is super hard especially for new parents with no former experience with children with disabilities." Another noted, "The system is too confusing. They need workers who really understand the system and help you navigate it." Finally, a third stated there is "no clear path for navigating the disability system and services that your child is entitled to receive." Many service providers also acknowledged the challenges families face.

> **"I think things are confusing for folks, I think there's lots of steps. It's a service navigation issue, where they get somewhere and they think once they are there are there – but they are really just at the first step. Can be very overwhelming."**
>
> – Executive Director of a Disability Program in Manitoba

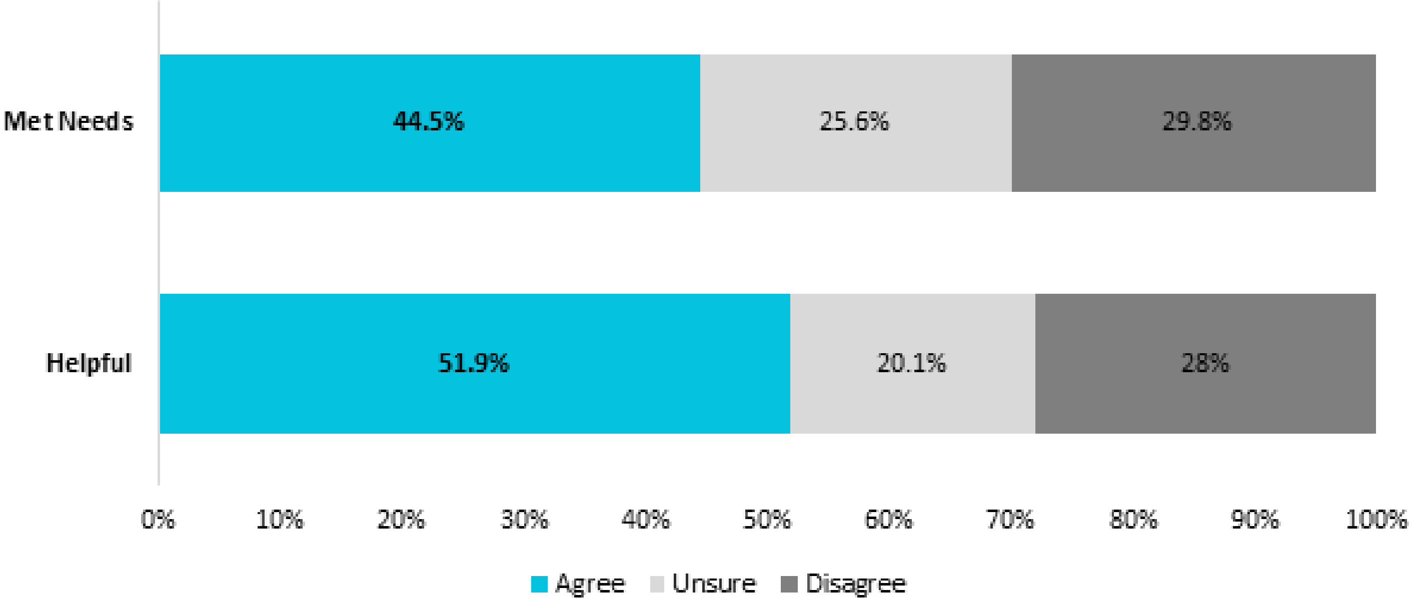
It is crucial that caregivers are provided with information about the resources available to their child and family as well as how to access them. CdS case managers are perfectly situated to support systems navigation and support families in understanding and accessing the services they are entitled to receive. The data collected, however, indicate there are simply too few CdS case managers to support the many families in need of support.

Satisfaction with Case Management

Research has demonstrated that a family-centred model is associated with greater caregiver satisfaction with services and service providers (Carrigan et al., 2001; Dunst et al., 2007; Espe-Sherwindt, 2008; S King et al., 2000; Law et al., 2003; Park et al., 2018). According to the caregiver survey, when asked about their level of satisfaction with the overall quality of disability case management services received (before the beginning of the COVID-19 pandemic), less than half (44.5%) of caregivers indicated they were satisfied or very satisfied (Figure 5).

Moreover, while the caregiver survey did not ask about satisfaction with service providers specifically, two questions provided information about caregivers' experience with their case managers. For instance, 52% reported they agreed or strongly agreed that their case manager was helpful (Figure 5).

Figure 5. Case Management, Caregiver Survey Responses (N=164)



Barriers to Improvement

Through investigation, interviews with stakeholders, data from the caregiver survey, and an analysis of CdS policy, we identified significant barriers to improving service delivery for children with disabilities and their families in Manitoba.

Diagnostic Assessments

Receiving a diagnosis is the first condition for accessing services. It is essential that wait-times for receiving diagnostic assessments do not become barriers for children with disabilities to receive critical early intervention services. When asked why the waitlists for assessments were so lengthy, one stakeholder described:

> **"Not enough people. Some of it is not enough money to hire the people [like] social workers and admin staff – if we had more money we could hire more of them and provide more supports. Other things that money can't buy. It's that we don't have enough child psychologists and developmental pediatricians that are available and/or interested to partner [with the Child Development Clinic]. The shortage of child psychologists is a tremendous bottleneck."**
>
> – Staff at the Child Development Clinic

The cause of these long wait-times for assessment at the CDC, is due to the fact that the number of children who need to be assessed has out-paced funding and the clinic's ability to recruit the specialized clinicians who conduct the assessments themselves. The clinic currently employs seven developmental pediatricians who are able to conduct assessments; together they account for 4.5 full-time equivalent positions. Shortages in child psychologists, developmental pediatricians, and support staff are resulting in significant delays in diagnostic assessments which, in turn, delay, and ultimately may deny, access to crucial early intervention services for children living with disabilities.

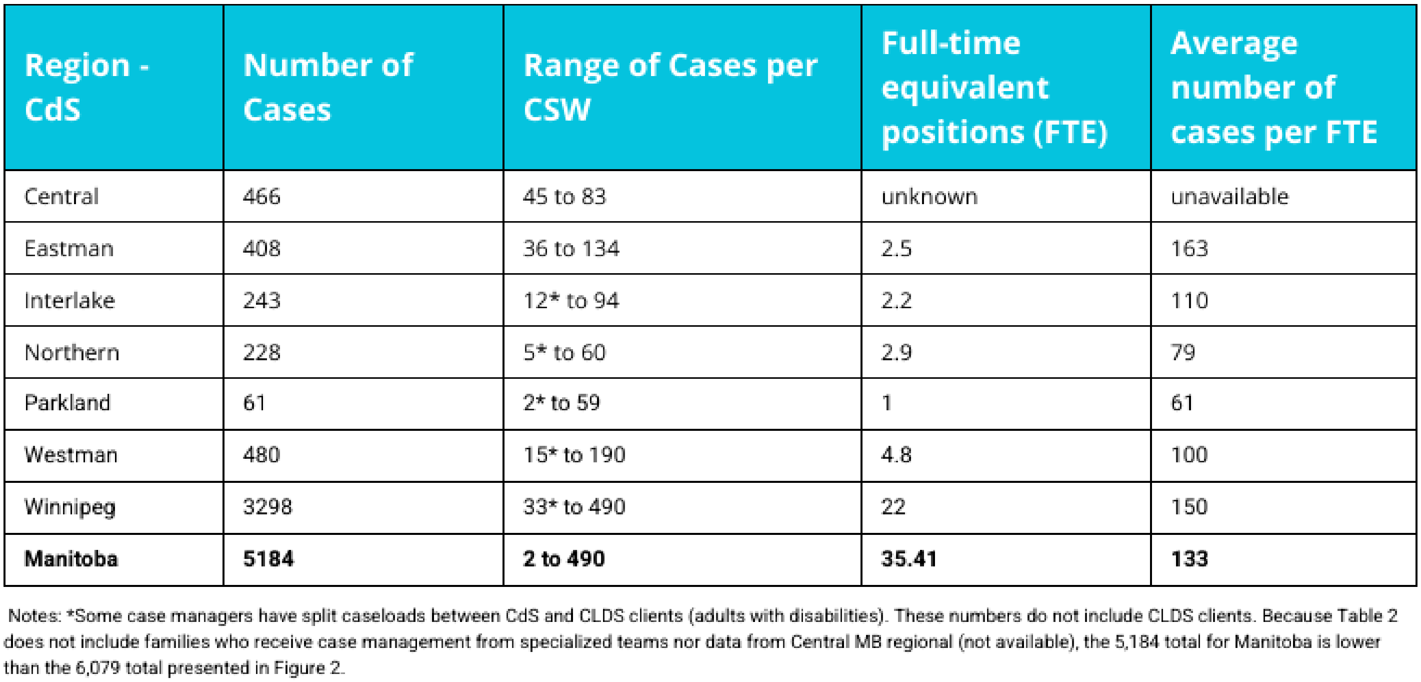
Caseloads

In order to implement an effective family-centred model, case managers need the time to engage with children and their families, create assessments and plans, and contact families regularly. In our caregiver survey, many families noted the hard work and dedication of CdS case managers.

> **"Our CdS worker is a very nice person, and we like her. But, she is overworked. We only have contact with her when there is a serious problem, and years go by when we don't have contact with her. It would be good to have at least an annual or semi-annual meeting with her. But, we get the impression that she is overworked."**
>
> – Caregiver Survey Respondent
>
> **"The people are great. The system is very broken."**
>
> – Caregiver Survey Respondent

Data collected from CdS indicate that caseloads for case managers in Manitoba average about 133 children per case manager, but can range from two to 490 cases each (Table 2). This is underestimating the total workload because several case managers, especially outside of Winnipeg, have caseloads with adult clients in addition to the children reported to the Manitoba Advocate for this review.

*Table 2. Manitoba CdS Caseload Summary as of July 21, 2020**



Region - CdS	Number of Cases	Range of Cases per CSW	Full-time equivalent positions (FTE)	Average number of cases per FTE
Central	466	45 to 83	unknown	unavailable
Eastman	408	36 to 134	2.5	163
Interlake	243	12* to 94	2.2	110
Northern	228	5* to 60	2.9	79
Parkland	61	2* to 59	1	61
Westman	480	15* to 190	4.8	100
Winnipeg	3298	33* to 490	22	150
Manitoba	**5184**	**2 to 490**	**35.41**	**133**

Notes: *Some case managers have split caseloads between CdS and CLDS clients (adults with disabilities). These numbers do not include CLDS clients. Because Table 2 does not include families who receive case management from specialized teams nor data from Central MB regional (not available), the 5,184 total for Manitoba is lower than the 6,079 total presented in Figure 2.

There is no agreement on what an ideal caseload should be to support children with disabilities, however, there is evidence on the negative impact of large caseloads on service delivery (Bogrnschutz et al., 2019). One literature review of best practices for working with at-risk young adults, including youth with disabilities, suggests caseload sizes of 20-30 per case worker for low intensity cases, 10 to 20 cases for moderate cases, and five to 10 cases for highly intensive services (Ministry of Social Development, 2011).

In our discussions with the Department of Families, it was clear that work has gone into the case weighting tool the department uses to triage and manage workload (CdS senior staff, Interview, March 16, 2021). As part of our ongoing follow-up to this systemic review and special report, our office will look to further analyze the complex tool that was built and is being used here in Manitoba. Specifically, we would seek to understand how the department's case weighting methods reflect its family-centred policies.

Assuming that the vast majority of cases are low intensity ones, we calculated that best practices would require approximately 202 case workers across Manitoba to adequately serve the 6,079 children enrolled in CdS during the 2019-20 fiscal year. During the 2019-20 fiscal year, 35.4 case workers across Manitoba (excluding specialized teams and the central region) were providing case management to 4,718 children and their families. Most importantly, caregivers across the province spoke to us about their experiences having difficulty connecting with their workers, that their workers seemed to be juggling many cases, and that the workloads result in less time to build relationships where children with disabilities and their families feel heard and understood. This feedback we heard from families may present an important opportunity for CdS to review its case weighting tools and work to ensure sufficient resources within the system so CdS workers can build relationships with families, undertake more assessments to better inform planning around formal and informal supports, and provide empathic counselling for families who are struggling.

> **"The recommended caseload for CdS workers is about 30 cases from my understanding. I only ever had double that or more."**
>
> – Former CdS Employee
>
> **"Freezes on hiring – it bears out when you can't meet needs because you don't have enough case managers."**
>
> – Former CdS Employee

The same staff member who spoke about freezes on hiring indicated the lack of resources and hiring freeze are some of the reasons why CdS began to prioritize and weigh cases after initial assessment. Families who do not have emergent or urgent needs wait longer.

Impact on Families

Several key informants who were interviewed noted CdS relies on families, particularly on families with low to medium needs, to reach out to its case managers to request supports. This was similar to what was seen in Emma's life. Though their case manager was responsive when they did contact them, Emma's family primarily received services in times of crisis. One social worker who specializes in working with children with disabilities stated:

“[T]here has been a real shift in services to being more consultative, where case managers will say — you call me when you need something — instead of reaching out to the families and seeing what they need. Probably because their caseloads are so big, but I think there’s issues with that. [CdS] will try to spin waiting for families to reach out as family focused. But actually, lack of proactive case management seems like an austerity thing to save money. The current case management is not good for families. By the time families call for help they are in crisis. It is so much harder to get back to a good place once a family is in crisis. If there were more prevention supports and services beforehand families wouldn’t need to get to a crisis point. It [case management] is reactive.”

– Social Worker

Children’s disABILITY Services is well situated to be the central coordinating body for the multidisciplinary teams of professionals providing care to children living with disabilities and to play a prominent role in systems navigation support to families. Currently, however, it is not resourced to fill this important role.

Summary and Recommendations

Family-centred care improves outcomes for both children with disabilities and their families. The framework employed by CdS acknowledges the importance of a family-centred model. Findings from Emma’s investigation, service provider interviews, the caregiver survey, and data analysis demonstrate that CdS may be unable to fully implement this model due to significant resource constraints.

All children living with disabilities have the right to effective government services that ensure substantive equality, to provide them with the same opportunities as others, including access to early intervention and care. At present, however, long wait-times for diagnostic assessments and high caseloads for case managers at CdS affect families’ access to early intervention supports and systems navigation.

Emma’s family had a CdS case manager who was caring and responded to family needs in times of crisis. There is no documentation, however, of CdS meeting the annual planning policies for the family once Emma entered school or as Emma’s needs escalated throughout her life. As Emma’s health deteriorated, her family’s needs increased. A proactive case management plan that included permanency planning may have helped Emma’s family avoid the crisis they experienced.

“Make a connection with me, build a relationship with me – this will be the most helpful for both of us.”

– Child Interview, age 11

Section 6: Respite

The following section focuses on the issue of respite services and presents findings based on Emma's child death investigation, data analysis, and consultations. Respite services are an essential component of care for children with disabilities, helping to strengthen families and reducing caregiver stress.

Section 6: Respite

Key Findings

- Respite is an important support for approximately 2,000 families a year in Manitoba. Respite helps keep families together and creates a better family environment due to reduced stress and improved coping. Research demonstrates that respite can improve the quality of life for both caregivers and children.
- Many families require more respite than they are currently receiving. The reasons for not receiving enough respite include difficulties hiring respite workers, not being approved for adequate respite, and a CdS respite budget that substantially decreased after the 2015-16 fiscal year.
- Many families reported that self-administered respite is not meeting their needs. Families and service providers report that families are sometimes not made aware of alternatives to self-administered respite.

Children's Rights

The provision of respite can be an important support. It enables families whose children with disabilities have complex and challenging needs to remain at home, as is the child's right (Article 9, UNCRC). Access to government-funded respite and supports ensures the provision of early and comprehensive supports for children with disabilities and their families, as enshrined in Article 23.3 of the CRPD.

Respite Services in Manitoba

In Manitoba, government-funded respite for families of children with disabilities may be provided by CdS, Manitoba Home Care, or, if the child is living in a foster home, by CFS. Manitoba Home Care provides respite for children with specialized medical needs. To be approved for respite funding from CdS, families of children with disabilities must be enrolled in CdS and there must be an assessed need for the parents to "have a break from the additional disability related demands of parenting a child with disabilities that cannot be met with available formal and informal supports"(Children's disABILITY Services, 2019). Respite may be provided by CdS in one of three ways to families who are approved to receive it:

1. **Self-administered respite** – Families recruit, hire, train, and pay a respite worker directly. As well, families are responsible for determining the hourly rate they pay respite workers and for submitting financial accounting and supporting documentation to CdS on a regular basis. Parents sign a legally binding contract with CdS stating that CdS will provide reimbursement to parents for respite up to a certain pre-approved amount during the contract's specified period. Families are responsible for all employment aspects, including obtaining appropriate background checks and provincial/federal employment requirements.

2. **Agency-delivered respite** – CdS can enter a Service Purchase Agreement (SPA) with a community-based agency to hire, pay, and manage respite workers for families. The only provider of agency delivered respite for CdS families is Community Respite Services.

3. **Direct Service Providers** – Direct service providers are recruited, interviewed, and hired by CdS resource coordinators to match the respite needs of the family. These providers have also been known as TIPS workers. CdS performs background checks and training, and is responsible for all other provincial and federal employment standards.

Evidence for Better Child and Caregiver Outcomes

Little research has been carried out about efficacy of different models of respite care delivery for children with a disability and so "no ready-made models of empirically validated best practice exist" (Merriman & Canavan, 2007). Nonetheless, studies have repeatedly shown that respite can lead to numerous benefits for children and youth (McConkey et al., 2013), including:

- **Improved behaviour and academic achievement** (Barnard-Brak & Thomson, 2009; McConkey, R et al., 2004).
- **Improved relationships with caregivers and reduced risk of abuse and maltreatment due to caregiver stress** (O'Brien, 2001; Robertson et al., 2011; Temple, 2015; Yoong & Koritsas, 2012).
- **Reduced caregiver stress.** Numerous studies report significant reductions in stress levels in caregivers receiving respite services (Black et al., 2010; Botuck & Winsberg, 1991; Brown et al., 2005; Chan & Sigafoos, 2001; Chou et al., 2008; Cotterill et al., 1997; Cowen & Reed, 2002; Gent & McDermid, 2012; Hartrey & Wells, 2003; Merriman & Canavan, 2007; O'Brien, 2001; Robertson et al., 2011; Shared Care Network, Bristol, 208 C.E.; Stalker & Robinson, 1994; van Exel et al., 2006; Whitlatch & Feinberg, 2006).
- **Improved family functioning and well-being.** Studies consistently show that respite has numerous benefits, including less family conflict (Chan & Sigafoos, 2001), improved marital relationships (Withers & Bennett, 2003), improved sleeping habits (Nankervis et al., 2011), and more opportunities for caregivers to spend time with their other children or family members (Robertson et al., 2011; Shared Care Network, Bristol, 208 C.E.; Stalker & Robinson, 1994).

Children's disABILITY Services Respite Policy

While there is no consensus in the literature about which type of respite service is best (Merriman & Canavan, 2007), CdS policy advocates for self-administered respite as the most effective and most desired method of delivery (Children's disABILITY Services & Malkowich, 2019). A CdS policy circular states, "the majority of families receiving CdS services will be encouraged to self-manage their respite needs. All new respite requests that are assessed and approved will be offered a self-managed model of service" (Children's disABILITY Services & Malkowich, 2019).

While current clients still have the option to use different delivery methods, new clients are encouraged to use self-administered respite with the goal to transition all clients to self-administered respite. This is very dangerous, particularly when the data show how little contact the caseworkers have with families. It is too easy to imagine a situation in which families struggle because they cannot get respite due to the workload they have to take on to organize respite in the first place. In internal CdS policy documents, the rationale provided for this shift includes both perceived benefits for families and financial benefits for CdS (Children's disABILITY Services & Malkowich, 2019):

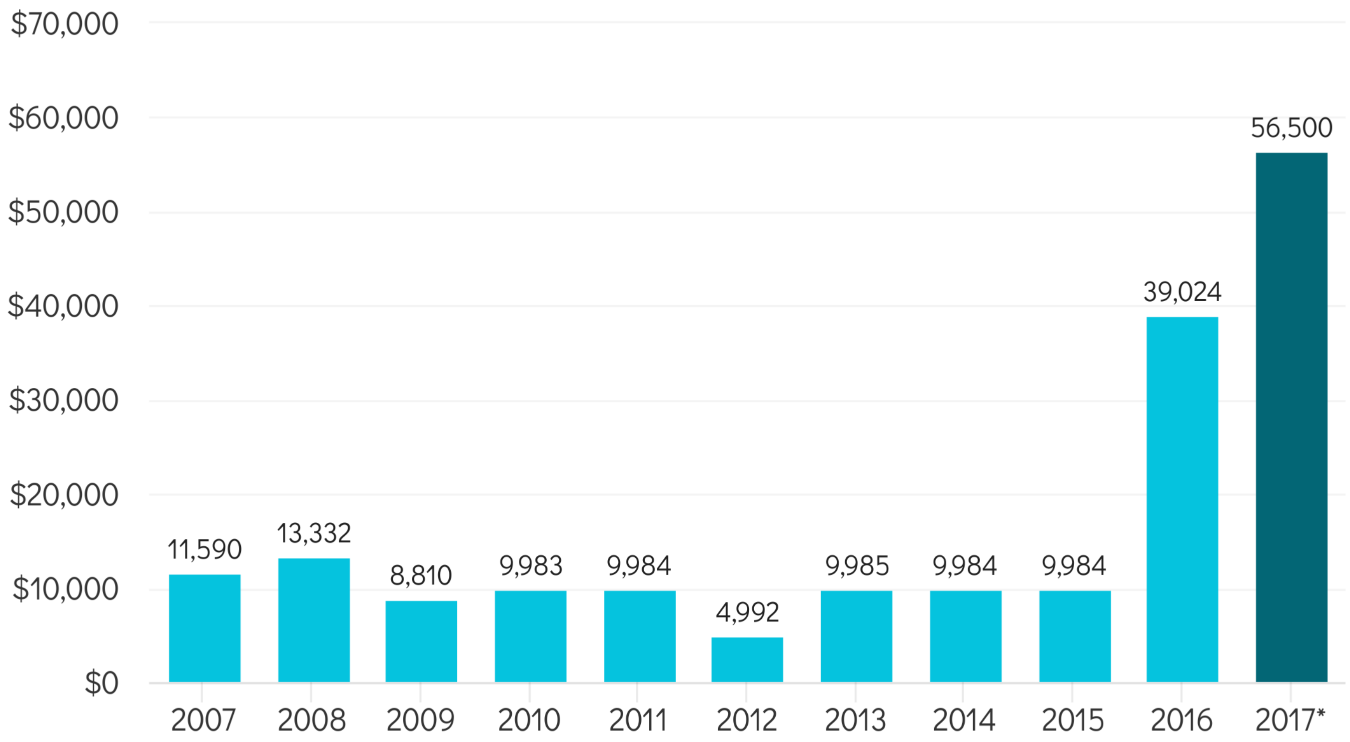
- "Under the self-managed model, families will have greater flexibility and control over whom they choose to provide respite, the dates and times respite is provided, and the ability to manage their allocated budget based within their assessed need."
- "Aligned with family-centred practice, self-managed respite puts families in charge of their service, as they are most often better suited to determine the best way to meet their needs."
- "Self-Managed respite is the most cost-effective way to deliver respite to families, which will help Children's disABILITY Services stretch its budget to provide more services to families."

Family-centred practice is about meeting families where they are at and providing options. This policy is not consistent with the individualized focus of family-centred practice. There are many families who are simply not able to self-administer their service – examples may include newcomers with language barriers and marginalized families living in poverty who experience other life challenges that limit their capacity to undertake the work associated with self-administered respite.

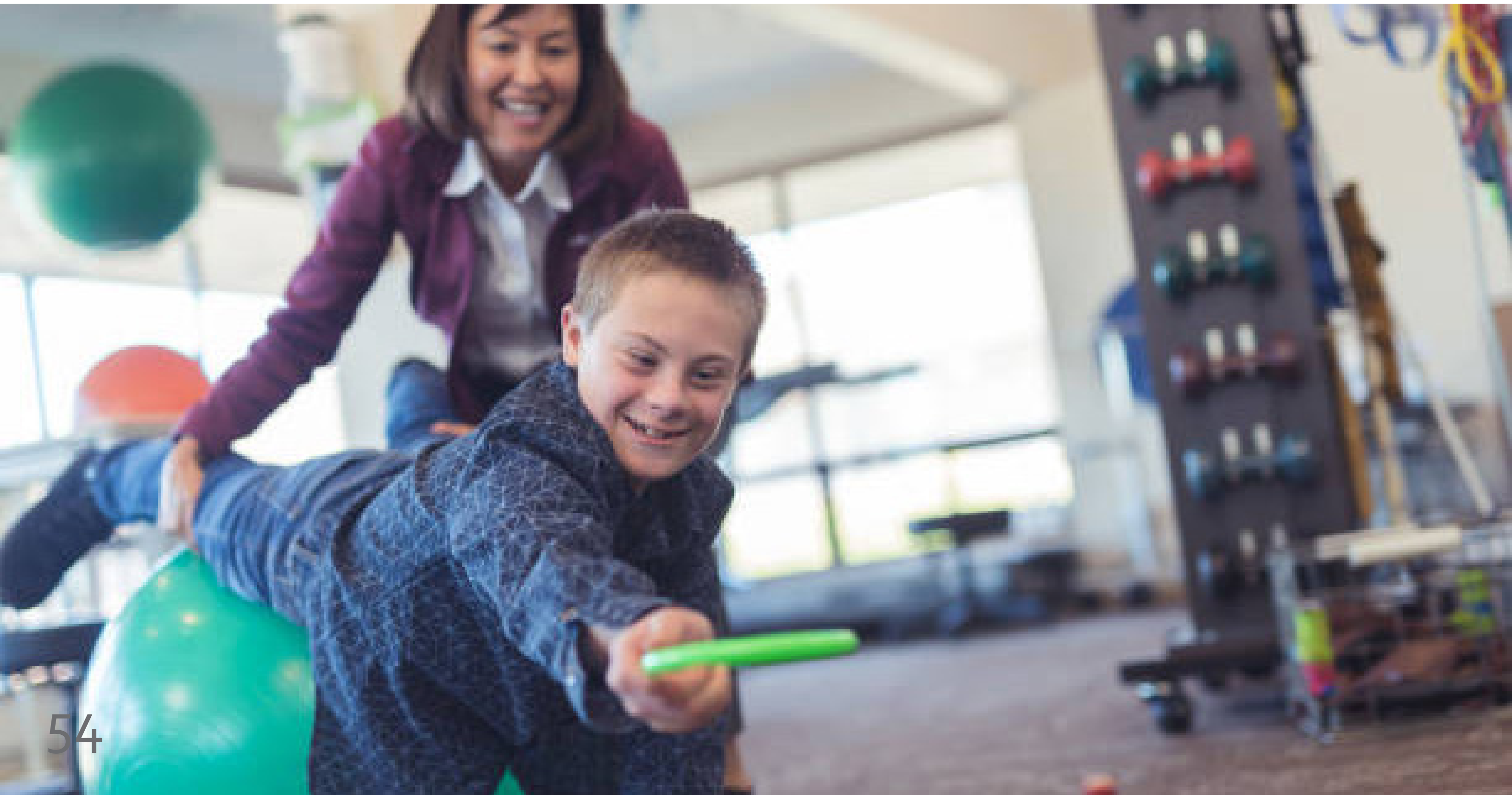
Experiences with Respite Services in Manitoba

Emma's family utilized self-administered respite providers throughout her life, as well as respite managed through CdS, in addition to a self-funded live-in care provider. We know that in the last three years of Emma's life, her family required drastic increases in respite funding to cope with her behavioural and medical needs (Figure 6). It is not uncommon for families to run-out of their budgeted respite in a fiscal year due to changes in family needs, and each time a family requires more funding, a new respite agreement is created. In the last three years of her life, Emma's family had 26 different respite plans. In the two years before her death, Emma's family's respite use doubled (see Figure 6). If Emma's family had used respite at the same rate during her last year of life for the remainder of that calendar year, her family would have used approximately $56,500 in respite.

Figure 6. Respite Expenditures for Emma by Calendar Year Approved



Note: * 2017 expenditures are projected based on respite expenditures on the months prior to her death. For 2007-2015, the expenditures are likely underestimated since they only include self-administered respite and not direct service respite. During this time period, Emma's family paid out-of-pocket for additional caregiving services.



Further, her family did not always find it easy to access respite services due to challenges in finding respite workers who could care for Emma in their rural location.

> **"They are having a great deal of difficulty finding people to work in this home. Partially because of the distance ([community] is about half an hour away), but mainly because of the complexity of the situation. DSP's are not wanting to take on an assignment that is medically complex as this one. ...Resource feels that this is something that is beyond the scope of what they can provide."**
>
> – CdS email, Emma's CdS file

Who Is Approved for Respite Services in Manitoba?

During the 2019-20 fiscal year, the families of 2,094 children were approved for respite. Many families sign multiple respite agreements with CdS each fiscal year because each time a family uses their budgeted respite amount, a new agreement is created.

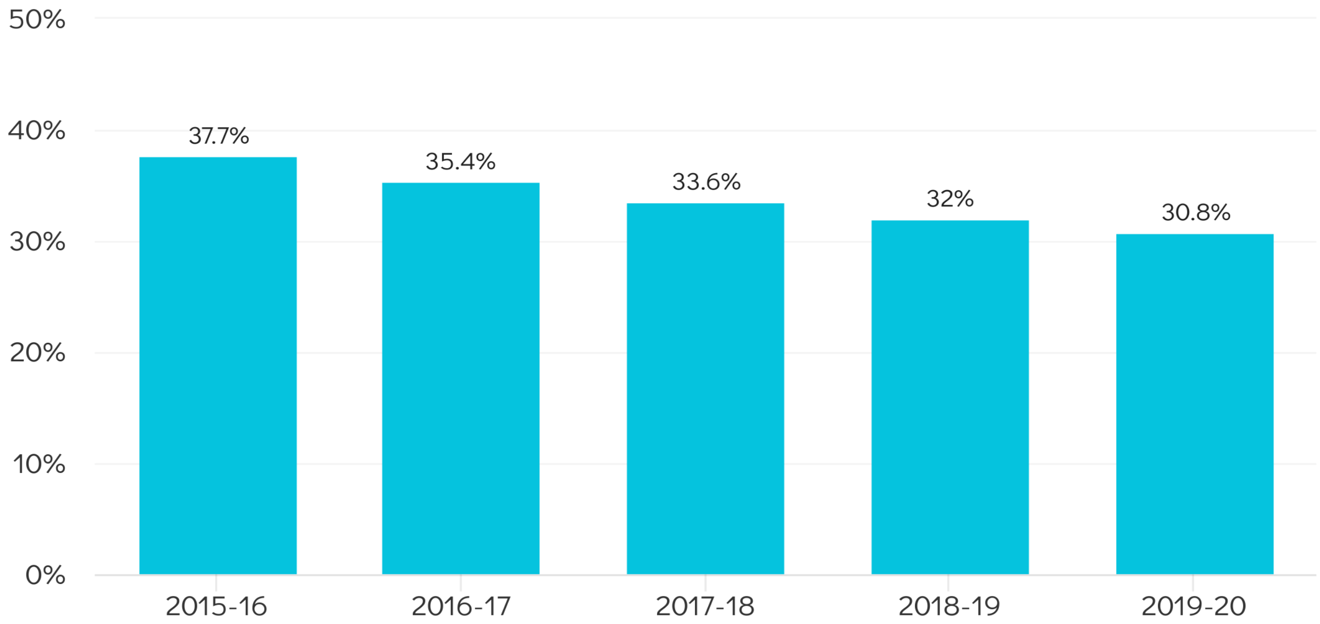
Documented reasons for respite approval remained similar year over year, with parent and/or family time being the most common reason for respite. Parent/family time was noted as a reason for respite in 94.6% of families who were approved for respite during the 2019-20 fiscal year. It is important to note that during the 2019-20 fiscal year several families were receiving respite for high-risk situations such as safety concerns (N=67), because the family was in crisis (N=39), and to reduce out-of-home placement or systems costs (N=29). The number of families noted to be in crisis receiving respite more than doubled between 2015-16 and 2019-20, from 17 to 39.

Children and families with the same diagnosis may need very different levels of support. Though we do not know the level of need of these children by looking at CdS data, the caregiver survey results can provide some insight. According to responses, 56% of caregivers who received respite indicated that their child needs a high level of support compared to other children their age, and 33% indicated their child requires a medium level of support.

How Many Families Receive Respite?

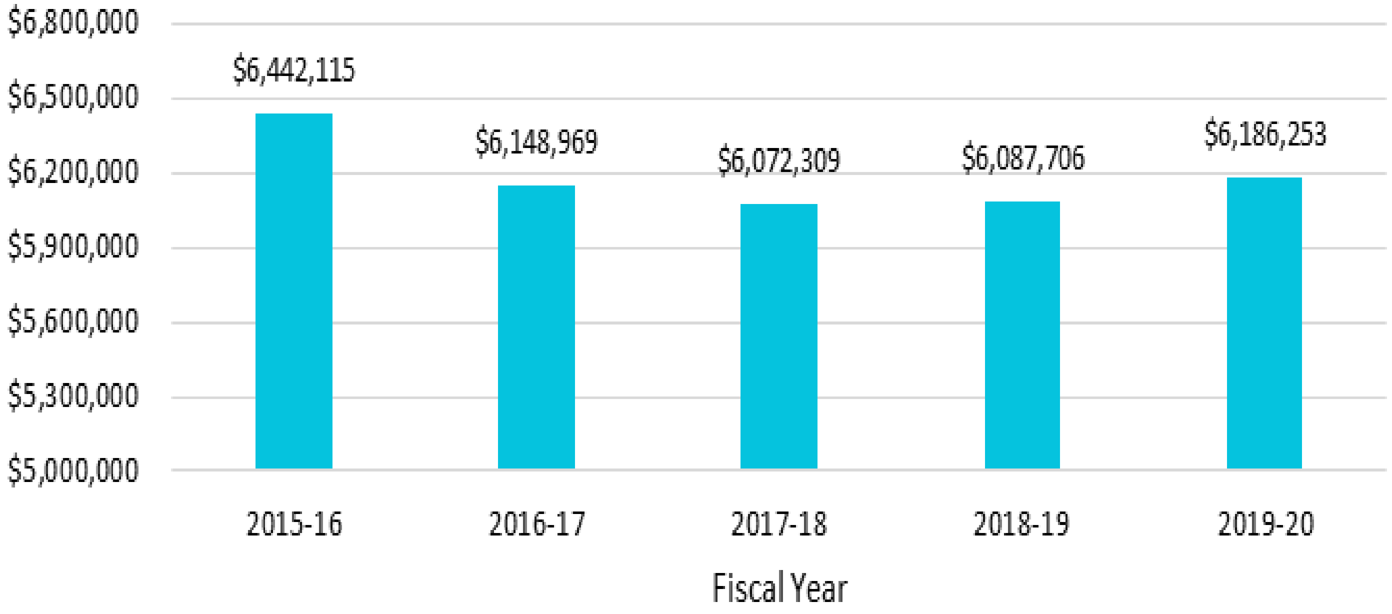
Both the total number of families who use respite and the proportion of CdS families who receive respite have decreased in the past five years (Figure 7), even though the total number of children enrolled in the program has increased each year. **It appears fewer families in Manitoba have been able to benefit from this important support in recent years.**

Figure 7. Proportion of CdS Families Who Used Respite by Fiscal Year



Typically, respite is the highest funded service (respite service costs are approximately half of the total annual CdS Program budget) and, a primary service for many families (Children's disABILITY Services, 2019). The highest amount spent on respite occurred in the 2015-16 fiscal year at $6.4 million. Respite the next fiscal year, in 2016-17, dropped by approximately $300,000. Between the 2016-17 and 2019-20 fiscal years, respite expenditures have remained relatively stable each fiscal year (Figure 8).

Figure 8. Total Respite Spending From CdS by Fiscal Year



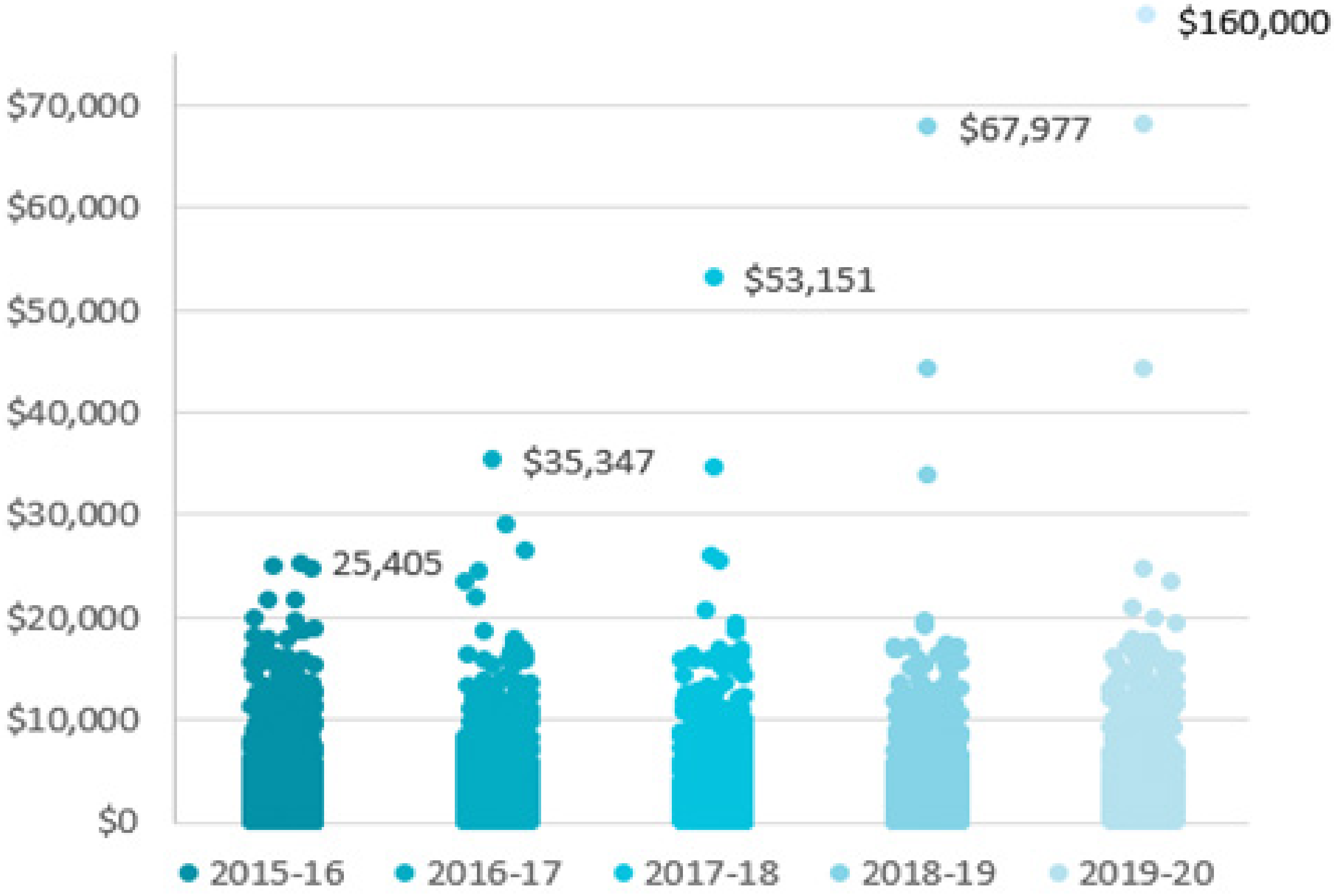
How is Respite Funding Allocated?

Even if a family is approved for respite, the amount of respite it receives is dependent not only on the family needs as assessed by their CdS case manager, but also on "the availability of human resources and funding" (Children's disABILITY Services, 2019a, p2). There is no CdS policy or procedure that describes the specific criteria a family needs to access different amounts of respite. CdS reported to our office that decisions on respite approval and amounts are made following a "conversation between the case manager and family." Many families who participated in the caregiver survey and received respite indicated they believed the approval and allocation of respite hours was too subjective.

The average amount spent on respite annually during the five-year period per family was approximately $3,200. This amounts to four hours of respite per week if the respite worker is paid $15 per hour. While the average annual cost of respite per family has remained virtually unchanged over the five-year period, the maximum a single child and their family receives has increased dramatically (Figure 9).

> **"My daughter is high needs yet for respite she's low in respect to hours given. At first she wasn't even going to be accepted. Epilepsy, gtube feed and global developmental delays and low mobility. I found it a bit irritating when children with [other needs] seem to get more hours. Like to know there [are] guidelines and how they actually base hours per child with disabilities."**
>
> – Caregiver Survey Respondent

Figure 9. Amount of Respite Spent Per Child by Fiscal Year



During the 2015-16 fiscal year, the maximum amount a single family received for respite was $25,405. During the 2019-20 fiscal year, however, the highest cost of respite provided to one family was $160,462. In other words, during the 2019-20 fiscal year, one family received six times more respite funding than the highest use family in the 2015-16 fiscal year and 48 times more than the average family in 2019-20. Outliers have extreme medical or behavioural needs and require intensive specialized supports.

> **"We need to shift the management from a business model to a person first process."**
>
> – Parent Interview

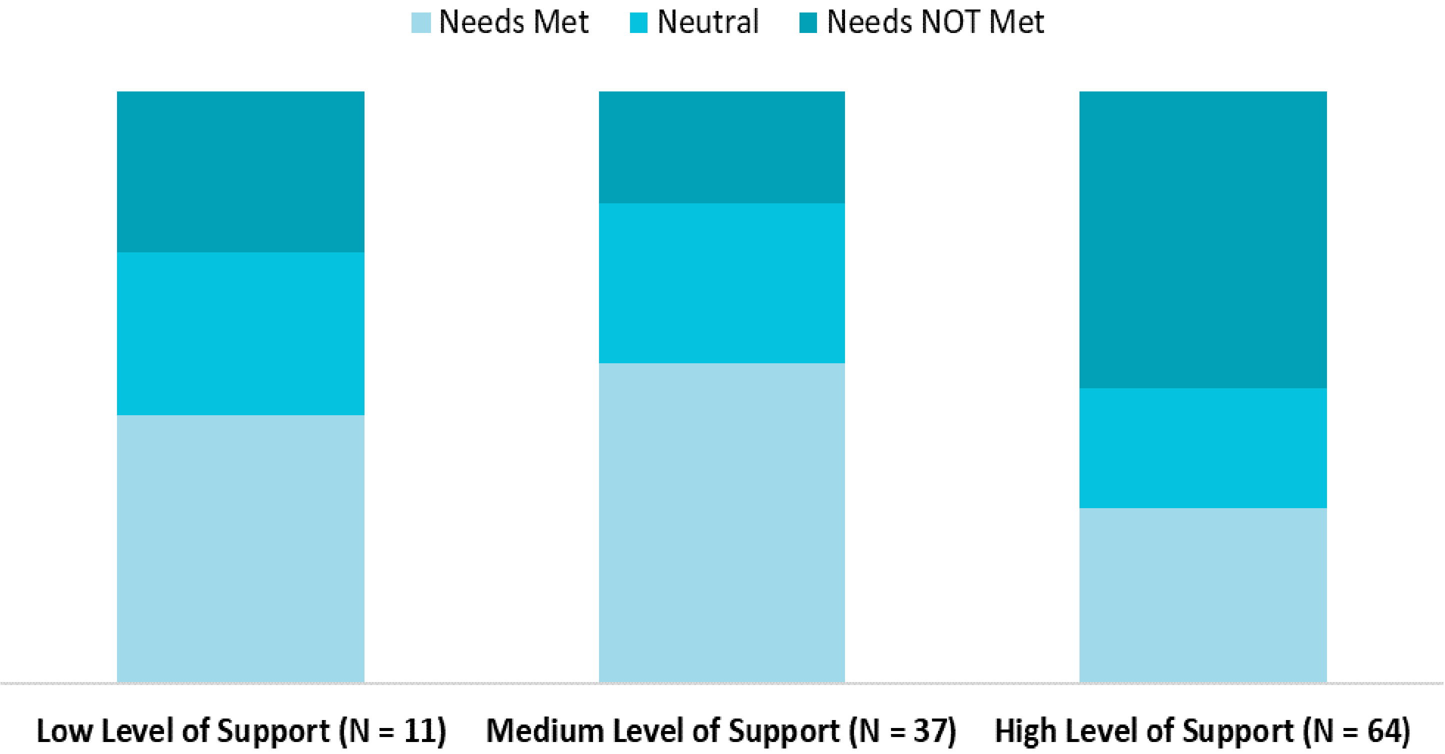
Is Respite Meeting the Needs of Families?

Only 39% of respondents in our caregiver survey indicated the amount of respite received met their family's needs. When asked if there was anything their family needed but were not getting, a common answer was respite or more respite hours. Families who received more respite hours were more likely to report that their needs were met ($p < 0.05$).

> **"[T]he fact that I get 4 hours a week at minimum wage to care for a 13-year-old who is 175 lbs. who needs help with everything is so unrealistic and so disrespectful. We must pay out of pocket. I've tried numerous times to get more money and more hours and get declined every time."**
>
> – Caregiver Survey Respondent

By contrast, families who perceived their child to have high needs (57% of caregivers who answered the question), were less likely to report having their needs met by respite (Figure 10). This suggests that allocation of respite funding may be particularly inadequate for children with high needs.

Figure 10. Caregivers' Perception of Respite Needs Met Based on Their Child's Level of Need



Self-administered Respite

CdS data show that there is an increasing number of families who were approved for any type of respite, but did not bill the department for respite services. In the 2019-20 fiscal year, 220 children were approved for respite services, but the funds were not spent. This may suggest families are facing challenges accessing respite services after they have been approved. A documented difficulty with self-administered respite is finding care providers, especially in rural areas (Spalding et al., 2006). This was also true in Emma's case.

> **"Respite is useless if I can't find anyone who wants to work or is qualified."**
>
> – Caregiver Survey Respondent
>
> **"[There are] no workers in our rural area so no respite. Very hard on families. Nothing being done to recruit workers."**
>
> – Caregiver Survey Respondent

Respite should be delivered in a way that is uncomplicated. Relying on families to find their own respite worker, manage their own respite care, and submit required documentation monthly may work for some families, but could add additional stress on families who are already overwhelmed. The additional work and challenges involved for families that are often associated with self-administered respite may not be worth its perceived benefits. As one caregiver indicated:

> **"The attempt to download respite care management onto the shoulders of parents directly undermines the plan's goals. It is supposed to provide RESPITE for families, but self-management requires families to find and hire workers who are often in short supply. It cuts the wages for those workers. It forces parents to become tantamount to employers, with all of the bureaucratic red tape that that entails. It is a stunningly callous and unwise practice that harms poorly paid workers and families with disabilities."**
>
> – Caregiver Survey Respondent

Alternatives Are Not Always Presented to Families

Although CdS policy states that other forms of respite, including agency-provided respite, are an option, many caregivers reported that they had not been presented with all options available, as one explains:

> **"We had to fight for every hour of Respite or Child Support Hour we ever got through Children's disAbility Services right up until we were introduced to CRS [Community Respite Services]. When we asked our worker why she had not told us about CRS, she mumbled something about not really liking to use them. We quickly learned that was not her call! Once we applied for the hours that the Director at CRS informed us that we may qualify for, we were amazed to find out, still through Children's disAbility Services, how many hours we could expect...like overnights which we desperately needed. Sadly, we have not been able to find anyone for overnights for [name of child], but, we, CRS and my husband and I, are working on it!"**
>
> – Caregiver Survey Respondent

The MACY caregiver survey respondents' experiences are consistent with information from stakeholder interviews, including one with a former CdS case manager who explained how staff are encouraged to offer self-administered respite first due to its cost-effectiveness.

> **"Self-administered respite would be the first thing that was offered because it is less expensive than having TIPS workers [Department of Families staff]. Self-administered respite is more cost effective for CdS.**
> **If families were unable to do the paperwork because of language or literacy or vision problems, I often steered away from self-administered respite because there is a considerable amount of paperwork with contracts to sign, audits, invoices."**
>
> – Former CdS Case Manager

Positive Feedback

It is important to point out that not all who participated in MACY's caregiver survey were dissatisfied with the quality or amount of respite services they received, and several respondents took the time to point out their positive experiences, which centred on positive relationships with respite workers and the quality of care.

“My respite workers were always caring people and I felt very safe having them look after my children…I always felt that I could contact her with any question or problem that might arise.”

– Caregiver Survey Respondent

“I am quite satisfied with my Respite, as I feel I have an awesome team. They engage my son, teach him and genuinely care for him.”

– Caregiver Survey Respondent

Barriers to Improvement

Self-administered Respite

The most often cited reason for encouraging self-administered respite is that it is aligned with family-centred practice. The family-centred model, however, focuses on building trusting relationships between workers and families in order to develop an understanding of families’ needs, strengths and capacity, and the changes they experience over time. The model recognizes that not all families are the same and that some have less capacity to take on challenges than others. Therefore, a blanket policy that shifts significant workload responsibilities to families may work for some families, but could be problematic for other families.

Families that have the capacity to take on the responsibility of self-administering their respite service can find it to be beneficial. For example, families can have “greater flexibility and control over whom they choose to provide respite, the dates and times respite is provided, and the ability to manage their allocated budget based within their assessed need” (Children’s disABILITY Services, 2019). This is also what senior departmental staff described as the benefits of self-administeed respite when we met with them (Department of Families, Interview, March 11, 2021).

It is notable, however, that some families reported never having been informed of the other respite options that may have been available for them to consider.

“Respite is to help families out and me having to do self-managed care, is not a help. It only adds more work for the families.”

– Caregiver Survey Respondent

Finally, according to CdS policy, "families are not obligated to obtain security checks from service providers" (Children's disABILITY Services, 2020a), but if they do, CdS will not cover the costs involved. In short, not only can caregivers hire anyone without a background check, if they do administer any background checks, they must pay for all of the expenses incurred – in addition to costs for training, interviewing, and monitoring of their workers. Given that not all families have the resources to pay for security checks, some will be forced to forgo this recommended and important step. This may compromise children's right to a safe environment and protection from all forms of abuse (Article 19, UNCRC). Furthermore, when families self-administer respite, they assume full liability for any negative consequences associated with this decision, while CdS and government at large have no liability because they have transferred all decision-making to the family.

Self-administered respite is clearly a benefit to CdS from a financial and liability perspective, but it is not consistent with family-centred practice, the rights for children's safety, or the goals of respite services.

"A number of things like self-administered respite were being pushed as labour-saving initiatives. Responses to an ever-shrinking workforce. I know it's difficult, but our job is to serve. What we are doing [putting liability and work on parents] is taking short-cuts that put families, the program, and kids at risk. No, we shouldn't be doing that."

– Former CdS Employee

"The concept of respite or having an occupational therapist, those are things that people need to be educated on what's available. From a money saving perspective, it is cheaper not to tell people what is on the menu."

– Former CdS Employee

Low Wages and Hiring

Regardless of the respite model, the lack of increases in annual provincial funding for the growth in caseload volume and respite service has made it challenging for families, agencies, and government to hire respite workers. As one manager told our office, over the past 10 years there has been no meaningful increase in wages, even to meet inflation.

According to the current Government of Manitoba financial services guidelines for CdS (Government of Manitoba, 2019), self-administered respite workers are to receive minimum wage ($11.90 per hour) for those working with families requiring ‘minimal support’; $12 (plus $1 or $1.50) per hour for families requiring ‘moderate support’; and $12 (plus $2 or $2.50) per hour for families in need of ‘significant support’. Families that require ‘exceptional support’ are required to pay their respite workers $12 (plus $3) per hour. It is important to note that approval by the program director is required for families requesting ‘exceptional support’. By way of comparison, the starting hourly rate for agency-directed respite workers is $15.96 per hour.

Therefore, CdS has many families who are waiting for respite services because they are unable to find workers who want the position. This is especially true for families who have children with complex needs.

Summary and Recommendations

Respite is an important support on which many families rely. Substantive equality, a principle in Canadian law, in this context recognizes that to achieve equitable outcomes some individuals and families require more supports than others, including respite. Respite helps keep families together, and creates a better family environment due to reduced stress and improved coping.

Many families require more respite than they are currently receiving, particularly families of children with high needs. The reasons for not receiving enough respite include difficulties associated with self-managed respite such as hiring respite workers, difficulties being approved for adequate respite, and a respite budget that substantially decreased after the 2015-16 fiscal year. Further, the process for approving and allocating respite is not perceived by families as being transparent.

Families who are able to self-advocate or can afford to pay out-of-pocket for services, may fare better than families that are unable to do this. Effectively, this disadvantages the parents and caregivers that may need the most support, including single-parent households, low income households, newcomer households, and First Nations and Metis families.

Section 7: Alternative Care

The best place for children to live is at home with their family in an environment that can nurture and enrich them, and provide the emotional support needed for well-being. In some cases, however, children with significant disabilities and challenges may require a temporary or permanent alternative living arrangement separate from their family home.

Section 7: Alternative Care

Key Findings

- There is a gap in alternative care services for children living with disabilities in Manitoba.
- A continuum of community-based care options for children with disabilities who require it is necessary; there is no one-size-fits-all.
- Service gaps exist, especially for children who are ambulant and have significant behavioural challenges.
- Due to gaps in alternative care in Manitoba, child welfare is sometimes brought in to plan for and fund specialized placements.

Children's Rights

Children with disabilities are best cared for within their family. All families can benefit from breaks caring for their child; this may be especially true for families who have children with disabilities who require specialized care and support. Respite support services are important services that allow parents to take a break, assist children with disabilities to make developmental gains, relieve family stress, and maintain a healthy family environment. In some cases, however, remaining in the family home full-time is no longer tenable. Article 23.5 of the *Convention on the Rights of Persons with Disabilities*, provides the following guidance:

> State parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

The UN Committee on the Rights of the Child also emphasizes the important role extended family and communities, and in some cases foster families, have in caring for children with disabilities. In particular, the Committee emphasizes the need for governments to provide alternate caregivers with the necessary training and support to care for children living with disabilities (CRC/C/GC/9, 2007).

Alternative Care for Children with Disabilities

Alternative care refers to care that is partially or fully undertaken by caregivers outside the home. When they are part-time, alternative care arrangements are also referred to as out-of-home respite. Out-of-home respite can be an important service for families who care for children who have significant medical, behavioural, and/or sleep-related needs (McConkey et al., 2004).

Some experts in the field argue that a broader and more flexible conceptualization of respite services beyond respite provided in the home is needed, including out-of-home options (McConkey, R et al., 2004; James Anglin, Interview, January 15, 2021). More intensive respite services are sometimes required to help support families whose children have greater needs, so they can remain at home with their families as long as possible. Out-of-home respite that is regular and ongoing has the potential to delay costly and long-term out-of-home placements.

Full-time out-of-home care is not appropriate for all children with disabilities and their families; it can be a positive and necessary experience for some children (Dr. James Anglin, Interview, January 15, 2021). No country in the world has completely eliminated alternative care for children, which indicates that it has a place in the continuum of services to support children with disabilities and their families (Dr. James Anglin, Interview, January 15, 2021).

There are many different types of out-of-home care arrangements for children with disabilities across the world. A home-like living environment is best practice for children who need to be away from their family home for a period of time (Dr. James Anglin, Interview, January 15, 2021). Examples of different physical living arrangements for out-of-home short- and long-term care for children with disabilities include:

- Licensed homes that specifically care for children who require overnight and/or multi-day respite.
- Shared care, where a child lives part-time at home with their families and part-time with extended family or a foster family.
- Homes into which children with disabilities and their family move. The home is staffed to meet the child's specialized needs.
- Long-term group home settings with two or three children who live with long-term trained staff or foster parents to support their development and needs.
- Cottages where older youth and young adults live that are connected to staff quarters which are staffed 24/7.

Living arrangements should be tailored to the unique needs of children and their families. Experts consulted for this report agreed that communities should have multiple options to accommodate the needs of children who require out-of-home care. Wherever possible, children's out-of-home care should be provided as close to home as possible to maintain family and community ties (Article 23.5, CRPD). Several people we interviewed suggested a two-home model where the child stays in the family home part-time and part-time in a long-term foster home. This model is used in Ireland and is referred to as shared-care or home sharing with a host family.

Best Practices in Alternative Care: The CARE Program Model

A model from Cornell University – The CARE Program Model – is a best practice in the way services are delivered within an out-of-home setting for children with disabilities. CARE is a six-part multi-level principle-based approach that can be applied to different living arrangements, including single-family homes, group homes, or larger facilities (Cornell University Human Ecology, 2016). The six CARE principles are that arrangements should be: (1) developmentally-focused, (2) family-involved, (3) relationship-based, (4) competence-centred, (5) trauma-informed, and (6) ecologically-oriented.

According to CARE, the child's experience should be at the centre of everything and service providers ought to consider what experiences are important for the child and what their needs are that will support them to develop to their full potential (Dr. James Anglin, Personal Communication, January 15, 2021).

> **"I think that the idea that it's like a second home – where the parents and the care provider get to know each other well and there's continuity and family – I think it would serve families and children well."**
>
> – Executive Director of a Disability Program in Manitoba

Experiences with Alternative Care in Manitoba

As illustrated by Emma's story, there are limited options in Manitoba for children with disabilities and families who require out-of-home placements to meet their needs. This was a service gap identified by caregivers, as well as service providers.

Emma's Story

- During her pre-teen and teenage years, Emma's family struggled to provide an environment where she and her family could thrive, largely because of Emma's increasing behavioural and sleep challenges. The family reached out to Children's disABILITY Services for planning for entry into alternative residential care.
- CdS submitted a referral to St. Amant for out-of-home crisis-stabilization and long-term alternative care, but was told there was a two year wait and to 'check back' every few months.
- The family was in crisis and CdS requested CFS involvement in order to provide Emma with a specialized residential care placement because St. Amant did not have any available.
- There were no existing options in the community that could support Emma's needs and CFS reported it would not fund a new placement for Emma or provide direct care, citing a lack of assessed protection concerns.
- Emma died accidentally, two days before an emergency systems meeting was called to find an appropriate placement resource for the family.

Emma's experience of needing an out-of-home placement to support her needs is shared by other families in Manitoba. In MACY's caregiver survey, we found that nearly **one in five** (19%) of the caregivers who completed the question about alternative care indicated they had considered placing their child in residential care to meet their complex needs. A further **one in eight** (12%) parents who answered the question reported having considered placing their child in the care of CFS so they could receive long-term residential care that their family felt they could not provide.

> **"We are exhausted by a system that has broken us. We are unable to continue to care for our son at home and are in the process of a move to a residential placement."**
>
> – Caregiver Survey Respondent

Alternative Care Options in Manitoba

There are limited ways families in Manitoba may access alternative care for their children. The first – which does not require child welfare involvement – is through St. Amant, which offers both short-term and longer-term options.

Short-term and Overnight Care Out-of-Home

The majority of individuals MACY interviewed for this report identified the availability of overnight, out-of-home respite as a major gap in the continuum of supports for families who have children with disabilities.

The main overnight, out-of-home respite option is accessed through St. Amant. As of January 2021, St. Amant provides overnight respite for 10 children and youth with disabilities under 18 years old. Each child is allowed up to one week of respite per month, and respite must be booked six months in advance. St. Amant does not accept any ambulant children (children not confined to a bed), like Emma, for respite services.

> **"The respite program [St. Amant out-of-home and overnight program] cannot accept someone with behavioural issues and/or who are ambulant. This is a gap in the system. There isn't a resource in the province that provides respite to ambulant children."**
>
> – Executive Director of a Disability Program in Manitoba

Service providers shared that enhancing short-term and overnight out-of-home options for families is important to prevent entry into child welfare care.

> **"The point of out-of-home respite is – a lot of disabilities have behavioural issues – how you keep this family together – if you are putting in enough supports when the child is younger you are avoiding placement until the child is an adult versus a youth."**
>
> – Executive Director of a Disability Program in Manitoba

Crisis Stabilization

St. Amant's River Road Place residence includes a short-term crisis stabilization unit, however, placements there are not dedicated to children and youth. As of January 2021, two individuals who came to the unit as youth were residing in the crisis stabilization unit, and two others were first admitted as youth, but are now young adults. These two youth were exceptions to the norm because no other placement options were available for them.

Though the crisis stabilization unit is meant for short-term stays, the average stay is 538 days. The two young adults in the unit who were admitted as children have stayed over three years in the short-term unit (Executive Director St. Amant, Interview, January 12, 2021). These long stays in a unit intended as a short-term placement reveal there are not enough options available in the community to care for their needs (Executive Director St. Amant, Interview, January 12, 2021).

There are currently no options in Manitoba for crisis stabilization for individuals with disabilities who are ambulant.

Time Limited Alternative Care

St. Amant's River Road Place in Winnipeg is the largest residential care facility in Manitoba. As of January 2021, it was home to 104 residents, of whom 20 (19%) were children or youth. River Road Place has 20 dedicated beds for non-ambulant and medically fragile children located in a dedicated child, youth, and young adults unit. These beds are used mostly as a step-down from Children's Hospital until patients can be transitioned into the community. The average length of stay for children in this unit, as of January 2021, was 238 days. This means beds become available every eight months or so.

As noted, River Road Place does not currently accept any children like Emma who are ambulant and have significant behavioural needs. No children are admitted to units with adults, unless there are major extenuating circumstances and the children are near adulthood (Executive Director St. Amant, Interview, January 12, 2021). St. Amant currently does not have a formal waitlist, but instead reviews applications at monthly meetings. If a spot is not available, the team may make note and bring it up at the following month's meeting (Executive Director St. Amant, Interview, January 12, 2021). An additional two beds are dedicated to providing respite services to children who are non-ambulant with high medical needs. Individuals live on six units and in five cottages attached to the main facility. As of January 2021, there were 32 children receiving various alternative out-of-home care at St. Amant.

Full-time Alternative Care

Residential Care Licensing, a program under the Department of Families, is responsible for licensing all home shares and shift-staffed homes in Manitoba. The role of Residential Care Licensing is to ensure residences meet health and safety standards. Two provincial departments, Community Living disABILITY Services (CLdS) and CFS, can apply for approval to manage and create new supportive living resources in communities. CLdS only licenses their homes for adults 18 years and over.

CFS is responsible for residences housing children under 18 years of age, and only provides these residences to children who are in the care of CFS. Currently, CdS does not have the authority to license short-term overnight respite homes or longer-term residential homes for children with disabilities. Differing authorities and mandates have created a significant gap in the system. CFS lacks the knowledge and expertise in disability and CdS lacks the legislative authority to license homes and residential placements for children with short- and long-term care needs.

CFS manages residential placements for children through the Provincial Placement Desk (PPD). CFS informed our office that it views its mandate as being focused on children in need of protection and that CdS ought to be providing services to children with disabilities where no protection concerns exist. This leaves children who require out-of-home respite or longer-term placements in a difficult position because neither system currently has the mandate to fully meet their needs.

Emma’s case managers sent a referral to the PPD in an attempt to find her an out-of-home placement. Emma’s family was told that there was no placement available to meet her needs.

Full-time Alternative Care Through Voluntary Placement Agreements

The Child and Family Services Act (CFSA) currently allows for the placement of children living with a disability under a temporary care agreement with CFS, namely a Voluntary Placement Agreement (VPA) (Section 14(1)). Under a VPA, parents retain legal guardianship while child welfare agencies are responsible for care. This agreement allows parents to gain access to additional resources for their children, including placements and overnight respite.

The current CdS policy allows a maximum of five days of overnight respite in a row, and no more than seven total nights in a month (Children’s disABILITY Services, 2019a). When a family needs more than the CdS policy maximum or their respite needs become too great for CdS to fund, CdS will approach a family to consider CFS involvement. Once in the care of a child welfare agency, a child with disabilities may access available placements licensed through CFS, including group homes or foster homes. Just because a child requires significant supports to remain in their home, as is their right under the *Convention on the Rights of Persons with Disabilities*.

> **“Disability specific licensing for children is a huge challenge – if that challenge could be alleviated – it would open up so much more for some of the families.”**
>
> – CdS Management

Foster Homes

Child welfare agencies utilize the PPD to find placements for children who come into care of CFS. In addition, some agencies also have their own roster of foster homes they manage and in which they can place children. For children with disabilities, St. Amant also has a small Emergency Foster Services program.

All children who enter into the care of CFS are assessed for the level of care and services they require to meet their needs. Needs are assessed on a scale from 1 to 5, 1 being the lowest level of need and 5 being the highest level of need. Children who have significant needs, like Emma, apply for CFS level 5 funding. The number of foster parents who are able to support level 4 or 5 children in their homes in Manitoba is limited. The approval process for level 4 and 5 funding can be lengthy. The process to get Emma assessed for level 5 funding was initiated just prior to her death, but was not approved by CFS until after she had died.

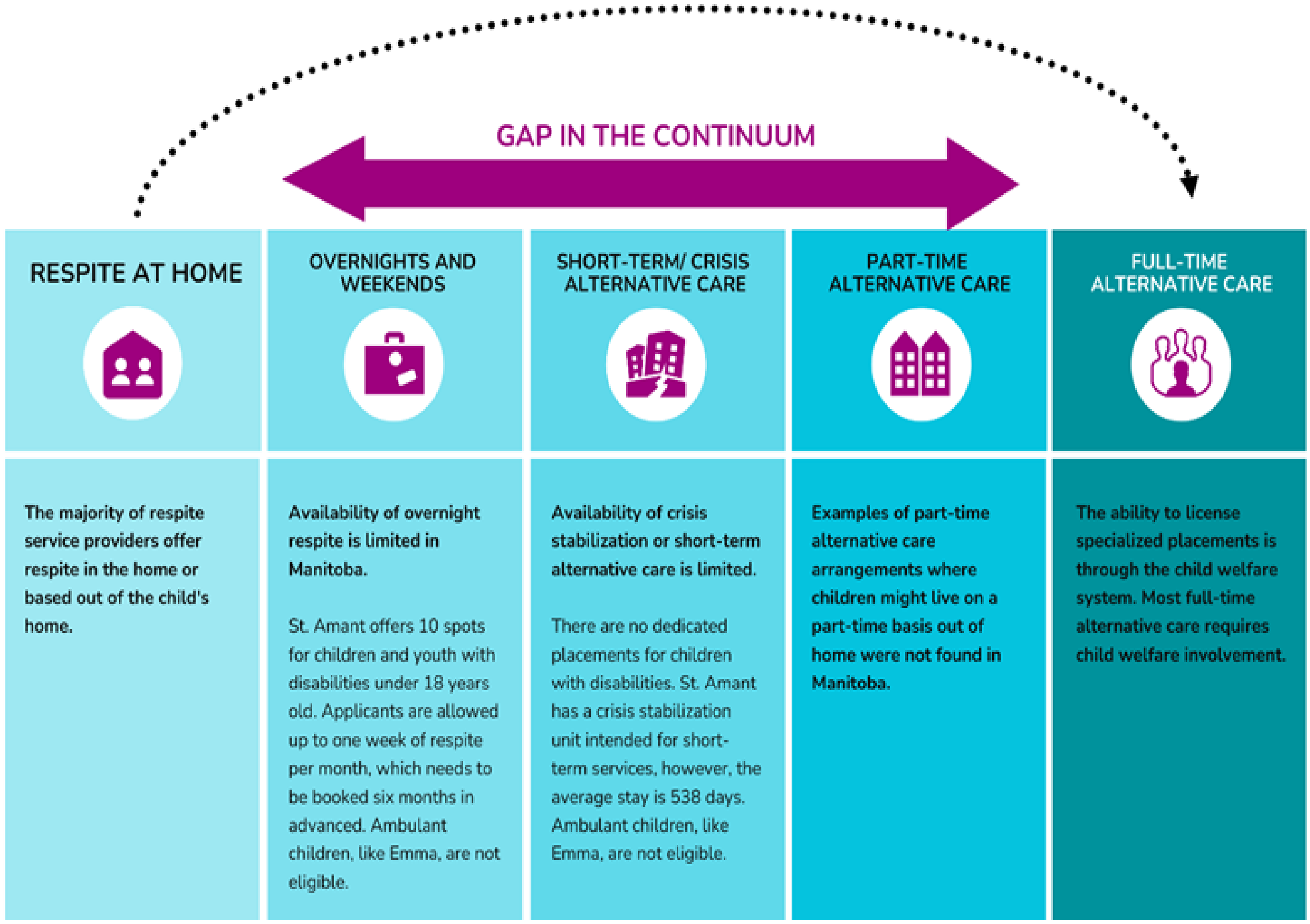
In a crisis situation, one mechanism to create an out-of-home placement for the child is to place them with a foster parent who has less experience caring for a child with disabilities, but who is augmented by external agency staff who provide additional supports. Another option is for child welfare agencies to utilize a place of safety. The CFSA defines a place of safety as "any place used for the emergency temporary care and protection of a child as may be required under [the] Act and includes treatment centres" (Section 1(1)). CFS may approach people familiar with/to the child to create a place of safety. Multiple people in the system tried to create a placement for Emma, but were unable to. This all too common scenario puts children with disabilities in environments that may not be able to meet their specialized disability-related needs. This was the topic of MACY's 2012 report about youth with complex care needs (Children's Advocate, 2012). In emergencies, children with disabilities may also access an EPR (Emergency Placement Resource).

> **"It's hard to find [a] placement that is structurally appropriate. CdS needs a bigger continuum of service. Services that CdS can buy are very limited – probably in part due to legislation."**
>
> – CFS Management

Barriers to Alternative Care

There are two interrealted barriers to accessing alternative care in Manitoba. First, there are simply not enough options and gaps in the continuum of alternative care options for caregivers (Figure 11). Second, CdS does not have the ability to license alternative care options and must rely on child welfare to develop specialized placements. The lack of authority by CdS to licence placements means that families and CdS have to engage with the child welfare system – a system necessarily focused on children in need of protection and without expertise in disabilities – to plan and explore services for their child.

Figure 11. Gaps in the Continuum of Alternative Care in Manitoba

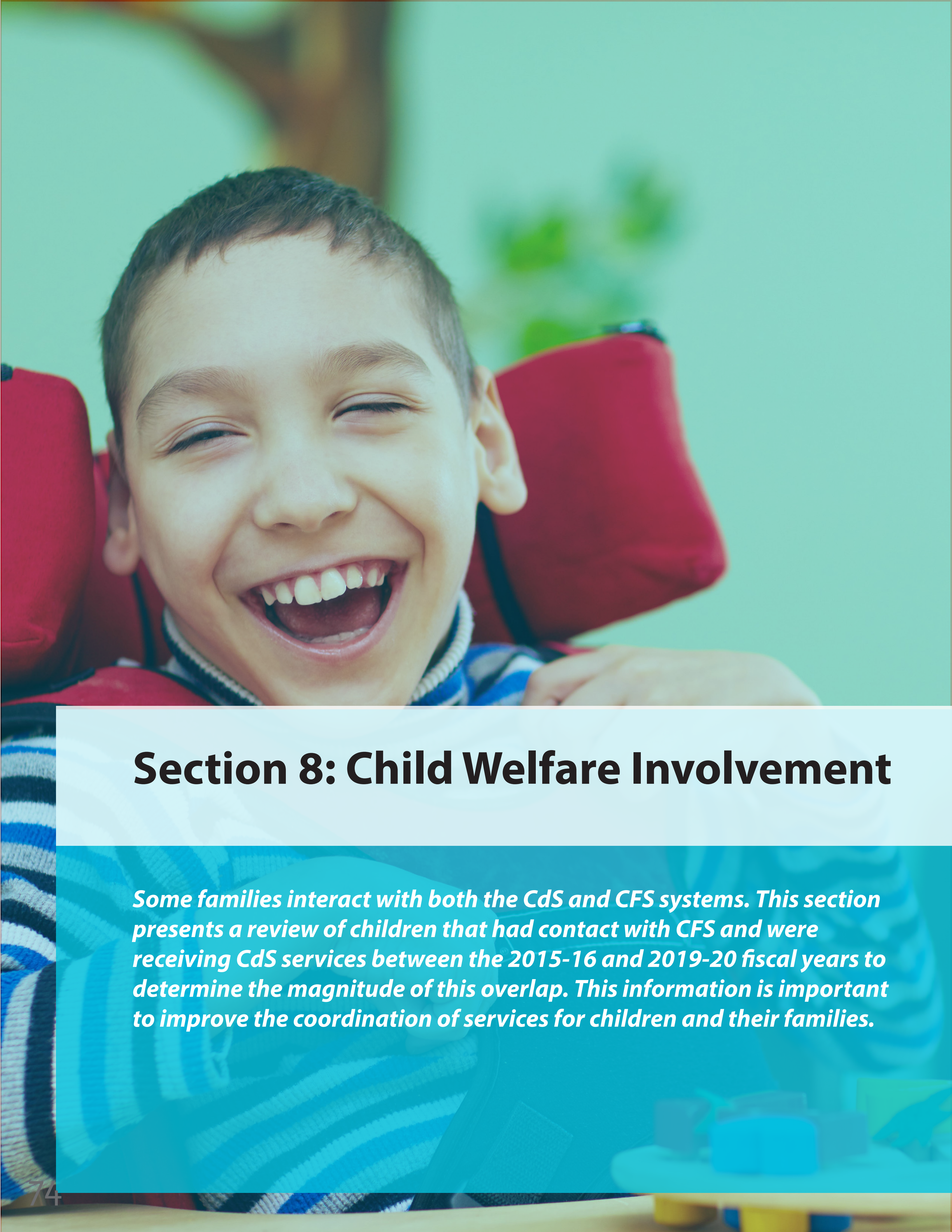


RESPITE AT HOME	OVERNIGHTS AND WEEKENDS	SHORT-TERM/ CRISIS ALTERNATIVE CARE	PART-TIME ALTERNATIVE CARE	FULL-TIME ALTERNATIVE CARE
The majority of respite service providers offer respite in the home or based out of the child's home.	**Availability of overnight respite is limited in Manitoba.** St. Amant offers 10 spots for children and youth with disabilities under 18 years old. Applicants are allowed up to one week of respite per month, which needs to be booked six months in advanced. Ambulant children, like Emma, are not eligible.	**Availability of crisis stabilization or short-term alternative care is limited.** There are no dedicated placements for children with disabilities. St. Amant has a crisis stabilization unit intended for short-term services, however, the average stay is 538 days. Ambulant children, like Emma, are not eligible.	**Examples of part-time alternative care arrangements where children might live on a part-time basis out of home were not found in Manitoba.**	**The ability to license specialized placements is through the child welfare system. Most full-time alternative care requires child welfare involvement.**

Summary and Recommendations

The alternative care options in Manitoba for children living with disabilities and their families are extremely limited and difficult to access. All children living with disabilities have the right to a family environment where they can develop fully.

Families of children living with disabilities require the necessary support, and sometimes that means out-of-home respite and placement options of alternative care. Unfortunately, these are rarely available in Manitoba. When families are unable to care for a child with disabilities, the government must take every effort to provide alternative care within the wider family, and failing that, within the community in a family-like setting (Article 23.5, CRPD). Manitoba families need a full continuum of supports.



Section 8: Child Welfare Involvement

Some families interact with both the CdS and CFS systems. This section presents a review of children that had contact with CFS and were receiving CdS services between the 2015-16 and 2019-20 fiscal years to determine the magnitude of this overlap. This information is important to improve the coordination of services for children and their families.

Section 8: Child Welfare Involvement

Key Findings

- On average, 47% of children served by CdS between 2015 and 2020 had current or historical contact with CFS. Of them, 28% were a child in care at some point in their lives.
- Children with developmental delay, those who live in single-parent households, and high users of CdS respite services are at increased risk of entering child welfare care, compared to other children and families in CdS.
- For 36% of children involved with CdS who came into care in 2019-20, their disability was a major contributing factor for entry into the care of CFS.

Children's Rights

Children with disabilities have equal rights with respect to family life. Article 23.4 of the CRPD states that:

> State Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. **In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.**

Systems Coordination

A specialized team called the Unified Team was established to coordinate services for families involved with both the children disabilities and child welfare systems (Children's disABILITY Services, 2020b). The Unified Team is hosted by Winnipeg Child and Family Services and co-locates some CdS and CFS case managers in one location. These co-located services are only available to children and families in Winnipeg.

While creating the Unified Team was a step in the right direction to coordinate services to families involved with CdS and CFS, each team member must follow the policies, procedures, mandates, and legislation of their respective departments or programs. As one CdS staff member communicated to MACY, co-location does not address the overlap and jurisdictional concerns in care coordination:

"Systemically our programs are designed to clash from time to time because we are all following our own mandate. [It] is important that we recognize that our programs are designed as such."

– CdS Staff

Experience with Child Welfare Involvement in Manitoba

Emma's Story

- As Emma got older and bigger, the behaviours associated with her physical and mental impairments became more difficult to manage, and included incidents of self-harming and violence.
- Emma had difficulty sleeping through the night, a condition that worsened and began to affect the well-being of the family.
- During the last year of Emma's life, the family was in crisis due to the lack of available specialized alternative care placements and service options for Emma.
- CdS brought in CFS to plan for Emma and her family to transition to CFS care but jurisdictional issues prevented a seamless coordination of care.

Contact with Child Welfare

During the five years between 2015-16 and 2019-20, 46.6% of children enrolled in CdS had contact with child welfare at some point in their lives. We found that a total of 3,967 children in CdS had a contact record on CFSIS (Child and Family Services Information System). The percentage of children found in CFSIS and enrolled in CdS ranged between 49% (2015-16) to 43.9% (2019-20). Children who only appeared in CFSIS due to their family fostering other children or due to adoption were not included in these calculations. The type of child welfare contact was wide-ranging and could include a phone call to see if CFS offers a particular service or ongoing contact regarding a child in need of protection.

Entry into Child Welfare

Of the 3,967 children that were enrolled in CdS and had contact with the child welfare system, 1,109 (approximately 28%) had previously become or were currently a Child in Care (CIC). That means that over one in four children with a disability in CdS coming into contact with CFS enters care.

What Predicts Entry into Child Welfare?

Our findings suggest that some children with disabilities, including those who use high levels of respite service, have a primary diagnosis of developmental delay, and those from single-parent households have a greater likelihood of entering child welfare care. MACY used a nested case control design to determine if there are differences between CdS children who came into the care of CFS and those who did not (see Appendix C of the Online Supplement for technical notes).

CdS assigns each child a primary diagnosis upon acceptance into the program and we found that children who came into the care of CFS were more likely to have a primary diagnosis of developmental delay (47.6%) versus children who did not enter care (37.4%)($p = 0.02$). Family status was also associated with coming into the care of CFS ($p < 0.001$). For example, children in care were more likely to come from single-parent households than those not in care (53.8% vs. 25.7%).

Finally, receiving respite services in the preceding 365 days was associated with children coming into care (p = 0.002). Children that entered CFS care received more services (39.9% versus 35.6%). Interestingly, children who received between $2,500 and $4,999 of respite per year were less likely to come into care (4.35% vs. 12.2%). This may mean that for some children with low to moderate needs, a modest amount of respite is a protective factor that helps families stay together.

The Experience of First Nation, Metis, and Inuit Caregivers

Due to the lack of data available from CdS on the Indigenous ancestry of children receiving services, we were unable to know whether First Nations, Metis, or Inuit children with disabilities were more likely to enter child welfare care. Still, caregivers who completed the survey and indicated their child was Indigenous were more likely to have considered a placement with child welfare or to have had their child in care compared to caregivers of non-Indigenous children (p < 0.001). Of the 53 children who were actively enrolled in CdS during the 2019-20 fiscal year and became a child in care during active CdS enrollment, 29 (54.7%) were Indigenous (First Nations: 23, Metis: 6).

Case evidence from our Advocacy Services Program suggests that, in some cases, First Nations caregivers are encouraged to involve CFS in the care of their child with disabilities. For example, MACY received a referral from a school about a First Nations child with disabilities who the school thought would be better cared for outside the home. The family did not want their child to be brought into care or live out of the home. Instead, they wished to have more in-home supports for their child to remain at home. Our Advocacy Services Program advocated successfully to ensure they received supports in the home.

Why Do Children with Disabilities Enter Child Welfare?

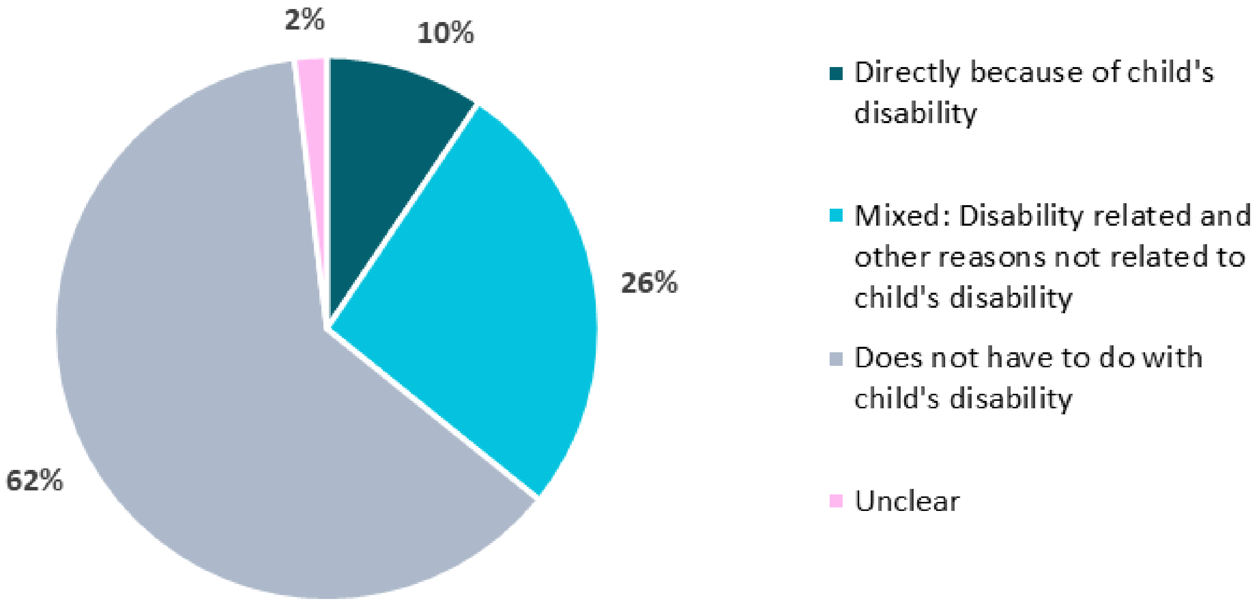
Understanding the reasons why children with disabilities enter child welfare care is essential to assess compliance with Article 23.4 of the CRPD – the right of children not to be separated from their family due to their disabilities. To determine the reasons for entry into the child welfare system, MACY reviewed the Child and Family Services Information System (CFSIS) records of a selection of 53 children involved with CdS who had a CIC file opened during the 2019-20 fiscal year. Notes were analyzed by three reviewers and reasons for entry into care were categorized as:

(1) abuse, neglect, or other non-disability-related cause
(2) a combination of disability and non-disability-related causes
(3) directly attributable to child’s disability

We found that, during the 2019-20 fiscal year, the child’s disability was the sole or major contributing factor for why 36% of children in CdS came in to care (Figure 12). Examples of disability-related entries into care include:

- The child with disabilities was violent towards siblings and parents were unable to provide adequate supervision to ensure safety of other children in the home. Child with disabilities entered care of child welfare.
- Child living with extended family under a private arrangement, but the extended family could no longer manage the child’s behavioural and medical needs, so the child entered child welfare care.

Figure 12. Reason for Entry into the Care of CFS Among Children With Disabilities Who Entered Care in the 2019-20 Fiscal Year (N=53)



Families in Crisis

Whether the child entered care due to an explicit need for additional disability supports from child welfare or due to protection concerns, the child welfare files describe families in crisis.

Reasons for a family being in crisis may be numerous and are unique to each family. In Emma's life, the family's sleep deprivation combined with Emma's behavioural challenges and the lack of alternative out-of-home placements put the family into a situation where they could no longer cope.

The distinction between disability-related and non-disability-related causes for entry into child welfare care is somewhat arbitrary. It is well documented, for instance, that children with disabilities are more likely to experience child abuse and neglect, factors which place them at risk of entering child welfare care (Dion et al., 2018). In turn, abuse and neglect are associated with caregiving or socioeconomic stressors (Conrad-Hiebner & Byram, 2020). Respite and support to parents, particularly parents who might be experiencing added stress, are essential considerations in the prevention of both child protection-related and disability-related entries into child welfare care for children with disabilities (Frederick et al., 2019).

"Kids with disabilities shouldn't come close to the CFS system – only if there are protection issues... [protection issues are] usually manifested because of a lack of support."

– Executive Director of a Disability Program in Manitoba

Barriers to Improvement

CFS is often involved when families are in crisis because other systems were not able to provide necessary preventative supports due to financial constraints and/or legislative and regulatory issues. The push and pull factors which lead to child welfare involvement for children with disabilities are described below.

Push factors: Under-resourcing Family Supports

The CdS Program has a total budget of approximately $31 million per year to provide services for children living with disabilities and living with their families in Manitoba. The total budget is broken into two components: (i) funding for external agencies and organizations to deliver specialized services for children, and (ii) Family Support Services (FSS) that are delivered by case managers to individual families across Manitoba. FSS are the focus of the CdS services described in this report and receive approximately $13.0 million dollars of the total CdS program budget. The FSS budget supports approximately 6,000 children.

By contrast and for illustrative purposes, child welfare has a budget of $686 million per year and serves 9,849 children in care (Province of Manitoba, n.d.). In the current system, children with disabilities that require extensive supports cannot be accommodated within CdS' budget, so must be referred elsewhere or transferred to CFS. As one service provider stated:

> **"CdS caps out at so much per child (...) their budget can't do it – so, kids are forced to follow the money, not necessarily the system, that might best meet their needs."**
>
> – Executive Director of a Disability Program in Manitoba

For children requiring specialized supports, as was the case for Emma, CdS involves CFS – a system primarily designed to respond to children in need of protection – to enhance supports. As one service provider stated:

> **"CFS tries to add and supplement services and funding when CdS maxes out. CFS wants to help stabilize families so they don't come into care... I think we really push back to the point where it's a crisis when kids come to care, which isn't helpful. We are throwing supports at kids, but the type of supports that we can provide may not be enough or not enough of the right types of support."**
>
> – CFS Management

CdS and CFS receive very different levels of funding for the populations they serve and the services they provide. This difference of funding, is an important factor for understanding why CdS seeks CFS participation in (i) 'topping up' respite allocations for children enrolled in CDS, and (ii) pursuing early CFS involvement in planning the transfer of responsibilities from one system to the other when specialized supports are needed. These factors contribute to the entry of children with disabilities into child welfare care.

> **"Another concern we hear is that families have to be in crisis to get something – those are challenges that aren't easy to reconcile. I think it makes sense that families who are in crisis do get the most supports. But we shouldn't have to wait until they are in crisis."**
>
> – Former CdS Employee

Pull Factors: Legislative mandate of CFS

While CdS has no legal mandate or stand-alone legislation to govern its services, child welfare, as stipulated in *The Child and Family Services Act* (CFSA), has a mandate to provide voluntary support to families of children living with disabilities. In particular, through Voluntary Placement Agreements, the child welfare system has the ability to provide services for children with a "chronic medical disability requiring treatment which cannot be provided if the child remains at home."

Hence, if treatment or services for a child with disabilities cannot be provided in the home, for whatever reason, child welfare –by law – can be invited to have a role in the care of children with disabilities, despite this being considered a system of last resort. Further, the child welfare system is able to license and fund specialized placements under the CFSA. This legislative structure works as a pull factor towards child welfare involvement for children with disabilities that need specialized out-of-home care.

The Child and Family Services Act (CFSA) Voluntary Placement Agreement

14(1) An agency may enter into an agreement with a parent, guardian or other person who has actual care and control of a child, for the placing of the child without transfer of guardianship in any place which provides child care where that person is unable to make adequate provision for the care of that child

(a) because of illness, misfortune, or other circumstances likely to be of a temporary duration; or
(b) because the child
(i) is a child with a mental disability as defined in *The Vulnerable Persons Living with a Mental Disability Act*, or
(ii) is suffering from a chronic medical disability requiring treatment which cannot be provided if the child remains at home, or
(iii) is 14 years of age or older and beyond the control of the person entering into the agreement.

Addressing the Overlap

To address this overlap in mandates, while also safeguarding scarce resources, CdS does not provide funding, services, or case management support to children who are in care of CFS. In July 2020, CdS drafted a formal policy outlining that CdS would cease to provide service to children and their families up to 90 days of a child coming into care (Children's disABILITY Services, 2020b). Prior to the policy being formally drafted, CdS already had an understanding that services were not to be duplicated between CdS and CFS systems.

> **"CdS started in 1985. At that time, it was hoped that children in care would not have a duplication of case management services, and the mandate for CdS was to serve children who otherwise had no other supports available. We consult and provide early intervention services for children in care; however, CdS does not overlap or duplicate the services provided by CFS. I don't think it is about ceasing services, but rather the CdS services are very different from CFS, and address very different needs in a very different way."**
>
> – CdS Management

If CFS and CdS systems provide families with complementary services, receiving supports from both systems, if they were coordinated appropriately, would not be a duplication of service, particularly since CFS does not have expertise serving children with disabilities. While CdS says that services cease due to overlap, the CFS system believes that CdS support should continue and follow children regardless of which systems are involved in the child's life:

> **"Get experts [CdS] to provide the expert services that children and families need. Supports should not stop because [children and families] are involved with CFS. Why can't the CdS respite plan follow the child? If respite and other services followed the child it could be part of a reunification plan. A lot of families have caregiver fatigue but could be reunified with appropriate supports."**
>
> – CFS Management

Though CFS and CdS are both under the same provincial department, both systems are siloed. As CFS management stated: "We hope to figure out funding and policies not just in silos but how do we [CFS and CdS] collaboratively work together to ensure that children and families are responded to in a way that makes the most sense."

Summary and Recommendations

There is a large overlap between the child welfare and children's disability service systems (47%). Of those children that have dual involvement, 28% entered care at one point in their lives. Further, 36% of the children who entered care during the 2019-20 fiscal year while they were actively enrolled in CdS did so for reasons associated with the behaviours, impairments, or special needs related to their disability. This finding runs contrary to the right of children with disabilities not to be separated from parents because of their disability (Article 23.4, CRPD).

Some families are more likely than others to be involved with the child welfare system. Results show that children with disabilities in single-parent households and who had high respite needs have a greater likelihood of coming into care. Of note, Indigenous caregivers were more likely to report that their child was ever in care. When applying the principle of substantive equality to this issue, it is, therefore, important to recognize that to ensure equitable outcomes, some individuals and families may require more and/or specialized supports (Fong, 2017).

These findings point to the need for legislative change which ensures CdS has the powers and responsibilities currently conferred to child welfare, including the ability to license and fund placements for children with disabilities. Without legislative changes, families – and particularly marginalized families that have children who require intensive supports – will continue to be unnecessarily involved with the child welfare system in Manitoba.

> **"I believe that collaboration is needed with CDS, voluntary CFS, and mental health services. If there was more collaboration and less concern regarding who the "funder" is (the money comes from the same larger pot), children could remain in their homes. The costs for children (with exceptional needs) to enter care is greater than supporting them at home. My son in care would cost over 600k per year. With the plan that we currently have, that allows our son to be at home, it costs 200k. The cost to have my son in care, due to lack of supports would cost the govt 400k more than what they are currently spending. The travesty is that it took us a year and a half, and our son entering care for 4 weeks (26k spent), before we were given the supports needed. I fear for families that can't or don't know how to advocate to receive the services to keep their disabled child at home."**
>
> – Caregiver Survey Respondent

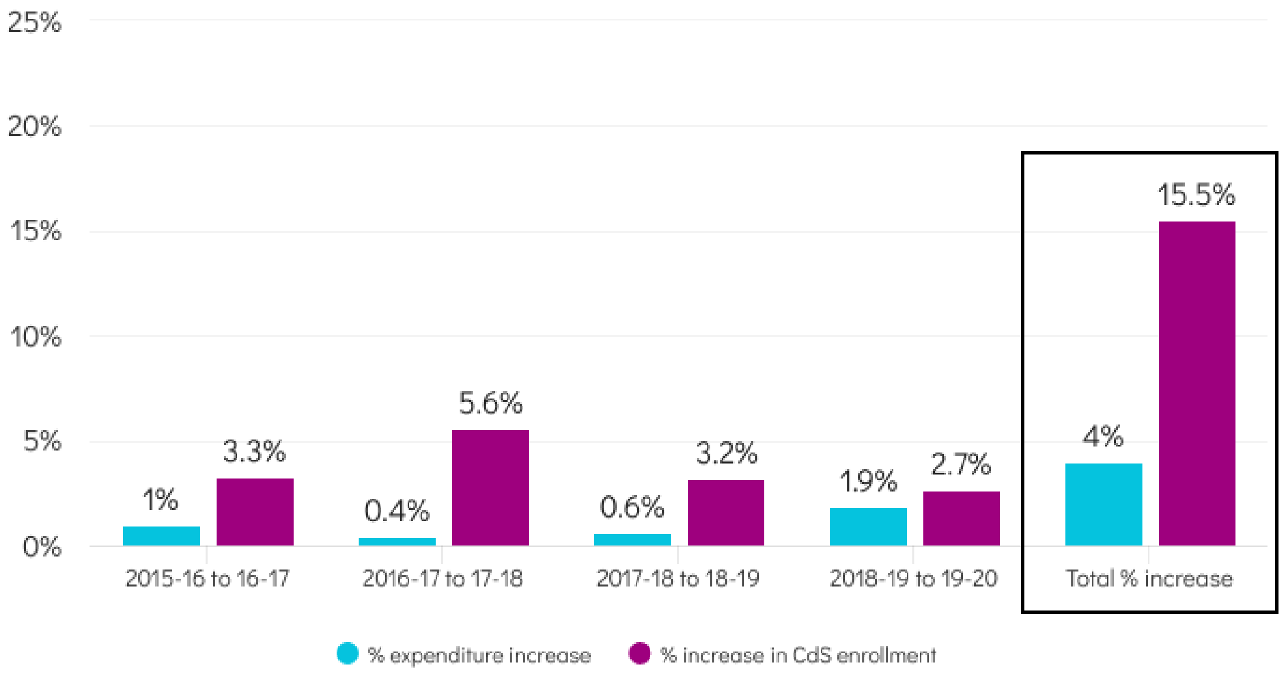
Section 9: Recommendations

A key responsibility of the Manitoba Advocate for Children and Youth is to develop recommendations that increase the effectiveness and responsiveness of provincial services (ACYA, s.31). This section outlines recommendations the Manitoba Advocate is issuing to the Government of Manitoba and community stakeholders with the goal of increasing the responsiveness and effectiveness of disability services for children, youth, and families in this province.

Summary

One of the most important findings of this special report is that children with disabilities and their families in CdS are getting less funding per capita than five years ago. As noted previously, between the 2015-16 and 2019-20 fiscal years there was a 15.5% increase in children enrolled in CdS. The total CdS budget, however, has only increased by 4% over this same period (Figure 13). According to CdS policy, access to CdS resources and services is dependent on the availability of annual funding and human resources, in addition to child needs (Children's Special Services, 2007). In other words, the combination of reduced program funding and increased need means that families are getting less services today than they were five years ago.

*Figure 13. Percentage Change in Children Enrolled in CdS and Annual Expenditures, 2015-16 to 2019-20 Fiscal Years**



Source: data on expenditures and number of CdS children were taken from Manitoba Families Annual Report for the 2015-16 to 2019-20 fiscal years.

Value for money

Investing in early and consistent supports for children with disabilities and their families is fiscally responsible. A cost-effectiveness analysis of Ontario's Intensive Behavioural Intervention (IBI) for children with autism found that expanding the program to all autistic children in Ontario would save the government $45,133,011 (Motiwala et al., 2006). For the same program, eliminating wait-times would increase access to early intervention, and as a result, increase children's IQ, which is estimated to produce lifetime savings of $267,000 per child (Piccininni et al., 2017).

Underfunding supports for families, which are protective factors for family health and for entry into child welfare care, encourages children with disabilities and specialized needs to enter CFS, a more costly system. On the other hand, resourcing the children's disability system by shortening wait-times, increasing respite, enhancing case management, and ensuring early interventions for children with disabilities is **a win-win-win for children, their families, and taxpayers** (DiBona & DiBona, 2017). Most importantly, it is aligned with fulfillment of the rights of children with disabilities and governmental obligations towards their care and the principle of sbstantive equality.

Shifting the Paradigm

Together, the recommendations presented in this report intend to contribute to a paradigm shift that transforms the children's disability system with supports that advance care for the families of children with disabilities.

Current State	Future State
Families of children with disabilities encounter barriers to access services they are entitled to receive.	The fulfillment of the rights of children with disabilities.

From	To
Wait-lists for diagnostic assessment and case management assignment delaying early interventions	Wait-lists are reduced, families receive supports while waiting for a diagnosis
Case management supports are under-resourced. Caseloads of 133 families on average prevents the implementation of family -centered care. CdS is unable to support systems navigation.	CdS is resourced to provide systems navigation services to families and family-centered care for children with disabiliites from birth and until adult services are introduced
Respite services are underfunded. Families receive less respite supports today than five years ago. Families have resources pay out of pocket for supports, those that cannot struggle.	A continuum of respite supports is created and allocated based on a comprehensive family needs assessment. All options are provided to caregivers. Policies for resource allocation are transparent.
Alternative care options are extremely rare. Caregivers that require out-of-home short-term, long-term, or crisis placements are unable to access timely supports.	A full continuum of flexible options is available to families which supports keeping families together.
Caregivers and families in crisis turn to child welfare for supports due to limits in the resources and mandate of CdS. Some children enter care to access supports associated with their disabilities.	CdS has a robust legal mandate to provide services to children and their families including the ability to license and regulate placements for children with disabilities without the need to involve child welfare.

Findings and Recommendations

Preventing Child Welfare Involvement

FINDING: *Children's disABILITY Services does not have a legislative mandate. This was identified as a significant barrier to ensuring the program has the power to provide services to all children with disabilities, as defined by the* Charter of Rights and Freedoms*. This is especially the case in relation to the ability to license and regulate specialized placements that can support the development of a continuum of respite and alternative care for families, preventing involvement with the child welfare system.*

RECOMMENDATION 1:
The Manitoba Advocate for Children and Youth recommends the Government of Manitoba develop and enact a legislative mandate for the Children's disABILITY Services Program, similar to Alberta's *Family Support for Children with Disabilities Act*, that empowers and resources Children's disABILITY Services to provide a broad continuum of supports for children living with disabilities and their families.

Details:

- This legislation should be based on the principles embedded in the *United Nations Convention on the Rights of the Child* and the *United Nations Convention on the Rights of Persons with Disabilities.*
- The Director of Children's disABILITY Services should be a statutory oficer with legislated powers to develop, license, operate, and provide oversight for alternative out-of-home short-, medium-, and long-term care (per Director of Child and Family Services).
- Consideration must be given to the transition from the child to adult disability service systems in Manitoba.
- A legal definition of disabilities consistent with the World Health Organization's definition and with Supreme Court of Canada decisions.
- Recourse for children and families by way of appeals of government decisions and processes.
- Ensuring adequate child-focused services and family support services from government.
- Ensuring that provincial resource allocation maintains substantive equality to meet the needs of children living with disabilities in Manitoba.
- Consult stakeholders, children living with disabilities and their caregivers in developing the legislation.
- Meaningfully involve First Nations, Metis, and Inuit governments and communities.
- Repeal s.14(1)(i) and s.14(1)(ii) of *The Child and Family Services Act* which govern Voluntary Placement Agreements of children with disabilities in child welfare care due to the behaviours or medical needs associated with their disabilities.
- Ensure CdS functions as the systems navigator for all families and children with disabilities and/or suspected disabilities.

Improving Coordination Between Systems

FINDING: *There is significant overlap between the children and families receiving services from Children's disABILITY Services and Child and Family Services. There is a need for formalized working agreements between the two systems to facilitate the effective coordination of services for children and their families.*

RECOMMENDATION 2:

The Manitoba Advocate for Children and Youth recommends that a protocol be developed between Children's disABILITY Services and Child and Family Services that clearly outlines mutually agreed upon processes for serving and jointly funding services for high needs children with disabilities and caregivers that receive services from both programs.

Details:

- All case management responsibilities for the child and family should be provided through Children's disABILITY Services for children who do not have protection concerns.
- Children's disABILITY Services selects and supports youth who receive out-of-home respite and alternative care funded and licensed by Child and Family Services, while the legislation is being drafted as per recommendation one.
- The protocol must revise Children's disABILITY Services policy that restricts the provision of Children's disABILITY Services for children transitioned into care with Child and Family Services to 90 days following the placement of the child.
- The protocol must identify lead case managers.
- The protocol to be based on the child-first principle which ensures immediate support for families whose children with disabilities have high needs that require the coordination of services between Child and Family Services and Children's disABILITY Services, minimizing impact to the family relationship.

Reducing Waitlists for Diagnosis

***FINDING:** Children with disabilities are entitled to early interventions. Delays in diagnosis may result in denials of some early interventions and services. Most pre-school-aged children in Manitoba receive assessments and diagnoses for neurodevelopmental disabilities through the Child Development Clinic. The Child Development Clinic receives between 1,500 and 1,600 referrals annually, and has a wait-time of approximately 12-14 months for an assessment.*

RECOMMENDATION 3:

The Manitoba Advocate for Children and Youth recommends that Manitoba Health and Seniors Care, Shared Health Manitoba, and Regional Health Authorities work together to create and resource a financially sustainable coordination agreement to reduce wait-times for diagnostic assessment for children suspected of having a disability, with the goal of wait-times less than six months between referral and diagnosis.

Details:

- Coordination agreement is an agreement to fund and enhance the delivery of diagnostic services for children that are suspected of having a disability.
- In line with Jordan's Principle the coordination agreement should address the geographic needs and issues of substantive equality to ensure that children living in rural and remote communities, including First Nations, Metis, and Inuit, also benefit.
- Recruit and hire additional child psychologists and developmental pediatricians to partner with the Child Development Clinic to increase the number of children that can be assessed annually.
- Research and develop incentives in partnership with the University of Manitoba's Department of Pediatrics to increase the number of trainees in child psychology and developmental pediatrics in the province after the completion of their residency.

RECOMMENDATION 4:

The Manitoba Advocate for Children and Youth recommends that Manitoba Families, Manitoba Health and Seniors Care, and Shared Health ensure that families whose children are placed on waitlists for assessments and interventions for disabilities receive system navigation supports through the Children's disABILITY Services Program while they wait.

Details:

- Shared Health and Manitoba Families jointly fund new systems navigator positions for children suspected of living with disabilities and their families.
- Eligibility criteria for access to a systems navigator is any child on a waitlist for assessments and interventions for a suspected disability.
- Manitoba Families conducts a developmental evaluation on the systems navigators within the first year of implementation.

Enhancing Case Management Services

FINDING: *The family-centred model of Children's disABILITY Services is consistent with best practices. CdS is well-positioned to provide systems navigation services to children with disabilities and their families. Due to high caseloads, however, case managers cannot always meet the needs of their families.*

RECOMMENDATION 5:
The Manitoba Advocate for Children and Youth recommends that Manitoba Families and Children's disABILITY Services review and address case management workloads to ensure case managers are able to implement internal standards and provide services that align with a family-centered service model.

Details:

- Conduct a workload analysis taking into account the ability of case managers to meet internal standards and geographic gaps in services.
- Once gaps are identified, develop a hiring strategy to address gaps in case manager positions.
- Ensure hiring practices promote Indigenous recruitment and retention, and consider designating positions for First Nations, Metis, and Inuit applicants.

FINDING: *Currently, CdS does not systematically collect information on First Nations, Metis, or Inuit ancestry. The current procedure at CdS is to record "registered Indian status" only, creating a gap in understanding the experiences of First Nations, Inuit, and Metis children with disabilities and their families.*

RECOMMENDATION 6:
The Manitoba Advocate for Children and Youth recommends that Children's disABILITY Services, in consultation with Indigenous experts in Manitoba, develop and implement a process for self-disclosure of First Nations (status and non-status), Metis, and Inuit ancestry, and track this information in case management records.

Details:

- Conduct a review of best practices of data gathering so First Nations, Metis, and Inuit Peoples feel safe in disclosing their ancestry identity.
- Ensure this literature review informs the self-disclosure process so that it is culturally safe and done in consultation with the First Nations, Inuit, and Metis communities.
- Ensure that case management records on inFACT are able to track First Nations, Metis, and Inuit ancestry fields.
- Analyze data to understand who is being served by Children's disABILITY Services and how well.
- Ensure services are tailored to reflect the cultural needs of who is receiving them.

FINDING: *Family-centred care, a best practice, acknowledges families as the experts. Children have the right to be involved in decisions that affect them as per Article 12 of the* United Nations Convention on the Rights of the Child*.*

RECOMMENDATION 7:
The Manitoba Advocate for Children and Youth recommends that Children's disABILITY Services develop a policy and process to collect regular feedback from the children with disabilities and the families it serves to inform service improvements.

Details:

- Conduct outreach and gain feedback from children and their caregivers, stakeholders and advocates prior to significant program changes, and/or if there are changes in service use trends.

FINDING: *The Children's disABILITY Services program does not currently have a complete program manual.*

RECOMMENDATION 8:
The Manitoba Advocate for Children and Youth recommends that Children's disABILITY Services complete a program manual and make this publicly available.

Details:

- The manual should include performance indicators specifying that case managers need to contact the families regularly via phone, video chat, email, or in-person.
- The manual should include performance indicators that include requirements to actively include children and youth in the assessment, planning and decision-making, to the fullest extent possible depending on the child's abilities (as per articleArticle 12 of the UNCRC).
- Revise Children's Special Services Policy on Assessment and Planning to ensure that the Family Needs Survey and Social Network Inventory Survey occur every six months, or are triggered by changing needs as communicated by the child or family.

Creating a Full Continuum of Supports for Families

FINDING: *Manitoba children with disabilities and their families are not able to access a full continuum of respite options.*

RECOMMENDATION 9:

The Manitoba Advocate for Children and Youth recommends that Manitoba Families and Children's disABILITY Services create and resource a strategy that reflects a full and flexible continuum of respite options from at-home respite to alternative care outside the home.

Details:

- The strategy should ensure that standard self-administered respite wages increase when minimum wage increases and ensure that self-administered respite wage allocations align with hourly wages of respite workers at Direct Service Providers (government) or agencies (Community Respite Services).
- Ensure families are fully informed about all respite options through their case managers and through publicly available materials.
- As part of the strategy, Children's disABILITY Services should develop informational resources on requirements for choosing self-administered respite, Canada Revenue Agency requirements, details about reimbursement for services to families, and other considerations in a checklist-style guide.
- Enforce and financially support the requirement for criminal record and child abuse registry checks for all respite workers, including self-administered respite staff.

Conclusion

Children with disabilities and their families in Manitoba are entitled to services that ensure substantive equality in their lives. The story of Emma is but one example that highlights the struggles Manitoba families face when accessing services for children with complex medical and behavioural needs. Hundreds of caregivers and dozens of service providers confirmed that this is an experienced shared by many families and children in Manitoba.

This report, the first systematic review of the disabilities system undertaken by our office, outlines service gaps in the areas of case management, respite, alternative care, and coordination between the child welfare and disabilities systems. The recommendations included in this report describe a pathway that would transform the children's disability system towards a cohesive continuum of services for children and their families. Importantly, recommendations seek to enhance quality of life, improve outcomes, and prevent children with disabilities from entering the child welfare system in the absence of protection concerns.

Working together, its our collective responsibility to uphold the rights of all children with disabilities and ensure **substantive equality.**

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