

APPENDIX A: DISABILITY SERVICES IN MANITOBA

Provincial Department Responsibilities

Department of Families

- Funding and management of Children’s disABILITY Services program, Child and Family Services, Disabilities and Health Support Unit, and Early Learning and Childcare Division.
- Funding of residential care at St. Amant, group homes, and foster homes.

Program/ Unit	Responsibilities (as they relate to disabilities)	Provides Funding For	Eligibility
Children’s disABILITY Services	<ul style="list-style-type: none"> • Determines eligibility for program • Case management / systems navigation • Conducting assessments to determine child/family needs • Approval of respite 	<ul style="list-style-type: none"> • Respite • Funding for services (e.g., ABA (applied behaviour analysis) program, clinical psychology, child development clinic, OT/PT) • Operation of Specialized Services for Children & Youth (SSCY) 	Birth to <18
Child and Family Services*	<ul style="list-style-type: none"> • Prevention services and family enhancement services to families • Provision of child protection services • Licensing and funding of residential housing for children 	<ul style="list-style-type: none"> • Child welfare authorities to fund agencies to provide the services • Services provided to children in/out of care and families • Respite for foster parents • Group homes/ residential care facilities 	Birth to <18 Agreements with Young Adults up to 21 years old.
Disability and Health Supports Unit	<ul style="list-style-type: none"> • Approval, management, and provision of disabilities equipment (e.g., wheelchairs) and supplies (e.g., incontinence supplies) 		All ages
Early Learning and Childcare Division	<ul style="list-style-type: none"> • Approves and coordinates inclusion support workers at daycares 	<ul style="list-style-type: none"> • Funding for individual inclusion support worker 	Birth to school-age or < 12-years old

Note: *This is a high-level summary of the services that are provided.

Department of Education

- Provides funding to school divisions to administer disability support services for students.

Program/ Unit	Responsibilities (as they relate to disabilities)	Provides Funding For	Eligibility
School Divisions	<ul style="list-style-type: none"> • Provide funding to schools • Hire and manage staff that provide disability services in schools • Manage contracts with service providers not employed by the school to provide disability services in schools 	<ul style="list-style-type: none"> • Disability services administered in schools including OT/PT, speech pathology, psychiatry/psychology 	School-age to <18
Schools	<ul style="list-style-type: none"> • Case management / Individual Education Plans (e.g., IEP) • Educational Assistants 	N/A	School-age to <21

Department of Health and Seniors Care

- Provide funding to regional health authorities that manage health care facilities that provide medical services related to children's disabilities.
- Provide funding for specialized care provided in the community, including those provided at St. Amant, SSCY, and home care.
- Reimbursement of physician charges related to the provision of medical services.

Program/ Unit	Responsibilities	Provides Funding For	Eligibility
Hospitals	<ul style="list-style-type: none"> • Provision of medical services 	<ul style="list-style-type: none"> • Medical services provided at hospitals (e.g.; clinical care by physicians, OT/PT, medication, psychology and psychiatry) 	All ages
Private practice pediatricians	<ul style="list-style-type: none"> • Provision of medical services • Coordination of medical care • Referrals to receive specialized assessments to determine disability program eligibility 	<ul style="list-style-type: none"> • N/A 	All ages
Physician specialists (in hospital or private practice)	<ul style="list-style-type: none"> • Provision of medical services • Conducting assessments used to determine disability program eligibility 	<ul style="list-style-type: none"> • N/A 	All ages

Major organizations/units within departments that are funded by government and provide disability services for children and youth, include:

Program/ Unit	Responsibilities	Some/All Funding Provided By	Eligibility
Specialized Services for Children and Youth (SSCY)	<ul style="list-style-type: none"> • Respond to referrals and determination of eligibility for CdS for Winnipeg residents • Provision of medical services • Assessments 	<ul style="list-style-type: none"> • Department of Health and Seniors Care • Department of Families 	Birth to <18
Manitoba Possible	<ul style="list-style-type: none"> • Service provision and case management; primarily for those whose primary disability is physical in nature 	<ul style="list-style-type: none"> • Department of Health and Seniors Care • Department of Families 	All ages
Community Respite Services	<ul style="list-style-type: none"> • Employs and matches respite providers with families 	<ul style="list-style-type: none"> • Department of Health and Seniors Care • Department of Families 	All ages
Manitoba Home Care	<ul style="list-style-type: none"> • Provides case management and home care to children who have high medical needs disabilities 	<ul style="list-style-type: none"> • Department of Health and Seniors Care 	All ages
Unified Team	<ul style="list-style-type: none"> • CdS and CFS case workers who work together to provide case management services to families/children involved with both systems. 	<ul style="list-style-type: none"> • Department of Families 	Birth to <18
St. Amant	<ul style="list-style-type: none"> • Provides community services for some children with disabilities including the ABA (applied behaviour analysis) program for autism • Provides residential care for high needs children, youth, and adults 	<ul style="list-style-type: none"> • Department of Health and Seniors Care • Department of Families 	All ages

APPENDIX B: LEGAL FRAMEWORK REVIEW

Statute	Governing Body	Relevance for children with disabilities
<i>The Education Administration Act</i>	Education	Instruction by correspondence for children that are unable to attend school due to disability.
<i>The Public Schools Act</i>	Education	Transportation support for pupils who are mobility impaired or unable to walk to school safely due to a learning or physical disability.
<i>The Community Childcare Standards Act</i>	Families	Funding for childcare programs to reduce or eliminate barriers to allow a child with additional support needs to fully participate in an early learning and child care program.
<i>The Accessibility For Manitobans Act</i>	Families	Reduction of physical barriers to access goods and services in the private and public sector with a goal to improve independence and social inclusion. (child and adult)
<i>The Adoption Act</i>	Families	Special services assistance for the cost of current or projected expenses associated with a physical or mental disability or the risk of developing one of adopted child.
<i>The Child And Family Services Act</i>	Families	A CFS agency may enter into an agreement with a parent, guardian, or other person (Voluntary Placement Agreement) for providing care to a child with a disability without transfer of legal guardianship. The director also holds responsibility for licensing foster placements and foster homes.
Child Care Facilities (Other Than Foster Homes) Licensing Regulation (CCSM C.C80)	Families	Regulation that applies to group homes, treatment centres, and specialized treatment units, including for children with disabilities, operated agencies for fewer than five children.
Foster Homes Licensing Regulation (CCSM C.C80)	Families	Regulation that applies to foster placements (under five children), including for children with disabilities.
The Protecting And Supporting Children (Information Sharing) Act, SM 2016, C.17	Families	Law that allows service providers to disclose information to facilitate collaboration and meet the best interest of the child.
<i>The Social Services Administration Act</i>	Families	Governs the provision of social services, including residential care facilities for individuals that have a disability or disorder prescribed in the regulations.
<i>The Advocate For Children And Youth Act</i>	MB Advocate for Children and Youth	Independent representative for children and youth in Manitoba, provides advocacy services to children with disabilities and their families. Also conducts child death reviews and investigations, child-centred research, youth engagement, and public education that is guided by the <i>United Nations Convention on the Rights of the Child</i> .
The Human Rights Code	MB Human Rights Commission	Protects individuals and groups in Manitoba from discrimination, defined as treating a person or group differently, to their disadvantage and without reasonable cause, on the basis of a protected characteristics, including disability.

Source: McColl et al., 2017

APPENDIX C: METHODS

1. Child Death Review and Investigation

The Manitoba Advocate is responsible for reviewing and investigating the deaths of children in Manitoba if that child or their family had received any reviewable service within a year of the death of the child (ACYA, s.11(1)(c)). To this end, the Manitoba Advocate receives notifications of all child deaths up to age 21 in Manitoba from the Office of the Chief Medical Examiner in accordance with the *Fatality Inquiries Act* s.10(1).

In October 2017, the Manitoba Advocate received notification of the death of Emma. Due to recent child welfare involvement, the Advocate's child death review and investigations program conducted a review of her death. Documents and case files provided by Child and Family Services (CFS) and Children's disABILITY Services (CdS) were included in the review. The Advocate's review was concluded in 2018-19, and based on the findings of the review and empowered by newly enacted legislation, the Manitoba Advocate launched a more detailed investigation thereafter. The review identified important themes, which are examined in this special report.

While multiple sources of information informed the work of the Manitoba Advocate for this special report, much of the work was grounded in the child death review and investigation into the services provided to Emma and her family.

2. Research and Data Analysis

In late June 2020, the Manitoba Advocate's Research Hub met with leadership at CdS. The objective of this meeting was to communicate the Manitoba Advocate's process and the scope of the review, as well as to understand how CdS collects information in order to request data.

This meeting was essential for assessing whether personal information or personal health information would be required pursuant to s.17(4) of the ACYA. Following this meeting, we assessed the scope of our information needs and a request for information was sent to CdS on June 30, 2020.

Information was requested for children and youth who applied for and/or was actively enrolled in Children's disABILITY Services (CdS) between the 2015-16 and 2019-20 fiscal years. A five-year period was requested to determine if services, as well as the makeup of children, youth, and families served by CdS changed over time. This time-period coincides with anecdotal evidence from disability service providers who suggested significant changes occurred over the five years. Information requested was related to characteristics of the children and families served, as well as the types of services they received. The data request had a special focus on two of the four themes of the report case management services and respite.

Data analysis

Our office received information throughout the months of August and September 2020. R Studio (statistical analysis software) was used to link and analyze CdS data, as well as data extracted from CFSIS. CdS provided MACY with lists of children who were referred, enrolled, closed, and who received specific services such as respite each fiscal year; all analyses were based on these CdS-provided lists. To determine the number of children that were actively enrolled at some point in each fiscal year, children

who had a status of “intake” but were determined ineligible for CdS were excluded. These children were excluded because they were never officially enrolled in CdS. Data from CdS were received in multiple spreadsheets; these data were linked, and anonymized prior to analysis.

A series of descriptive and statistical analyses were conducted using R Studio to understand the extent and nature of services provided to children living with disabilities. Statistical analysis conducted included poisson regression, chi-square tests, Wilcoxon rank-sum and fisher’s exact tests, linear regression, clustered logistic regression, and conditional logistic regression. Statistical tests were applied based on data and research questions.

Total fiscal year expenditures on respite were analyzed by adding expenditures from each respite plan ID for individual children within a fiscal year. All respite plans - self-administered, direct service provider and agency - were added. After adding expenditures for respite plans, if there were children who had less than \$12 of respite expenditures they were considered as having received no respite. A cut-off of \$12 was used because the minimum hourly rate was usually over \$12/hour, and CdS advised that very small expenditures could be accounting adjustments.

To determine differences between children who were ever in care and those who were not, MACY selected the 2017-18, 2018-19, and 2019-20 fiscal years to conduct analysis. This enabled MACY to look back at service utilization at least one year prior to the CIC date to see if the level or type of service predicted if the child went into the care of CFS. We were unable to look at children who had a CIC date prior to this time because we did not have service utilization information before April 1, 2015.

To investigate if certain characteristics were associated with entry in to care, we utilized a nested case-control design. Children in care (cases) were matched to children not in care (controls). The date when a child was put in care was considered the index date. The index dates were required to be during active enrollment in CdS (i.e., after an enrollment date and before a closure date (if applicable)). Cases were matched to three controls and on date of enrollment. Data were then analyzed using conditional logistic regression to examine associations.

Linkage to Child and Family Services (CFS) data

A list of unique children who applied for or were enrolled in CdS between the 2015-16 and 2019-20 fiscal years was developed. These children were manually cross-referenced by three MACY staff with the Child and Family Services Applications (CFSIS and Intake Module (IM)) to determine history of involvement with Child and Family Services. Appearing in CFSIS or IM indicates that the child or their families had historical or current contact with CFS. These children’s contact with CFS may or may not have been related to their disability. Children who were in CFSIS solely due to adoption or because their parents were foster parents were not considered to have contact with CFS. This information was recorded, linked to CdS data using R Studio, and analyzed. Once linked, data were anonymized.

Review of policies and procedures

Policies, procedures, Service Purchase Agreements (SPAs), and annual reports of agencies funded through SPAs were requested from CdS pertaining to program eligibility, respite, case management, systems coordination, and program delivery. Copies of SPAs related to residential care spaces for children and youth with disabilities were also requested and reviewed. This information was used to increase our understanding of the current state of the services and systems provided through CdS.

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 it deserves. A procedure dated May 6, 2020 (Circular Number: CDS #2020-10) 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."

3. Consultations and Engagement

Approximately 400 individuals were consulted through the development of this special report.

Parents and caregivers

On October 8, 2020, the Manitoba Advocate launched a comprehensive survey directed at caregivers of children and youth with disabilities in Manitoba ("caregiver survey") provided in English and French. The caregiver survey was developed in consultation with experts, including academics and executive directors of a disability-serving organization in Manitoba. It focused on theme areas and provided opportunities for open-ended responses. The caregiver survey closed on November 8, 2020 with 334 caregivers from across Manitoba providing responses (see Appendix C).

Children and youth with disabilities

The Manitoba Advocate recognizes the right of children to have a say in decisions that affect them (Article 12, UNCRC). It was important to include the voices of children and youth with lived experiences. Children and youth living with disabilities were identified for consultation through the caregiver survey and via social media. A total of 5 children and youth participated in the consultations. MACY's Youth Engagement team developed a unique process of participation for each child or youth dependent on their abilities – this sometimes involved written communication, visuals, and video chats. Parental consent was received and parents attended the sessions.

Professionals and government

A total of 21 current and former disability service providers and management were consulted through key informant interviews that focused on exploring systemic barriers and opportunities for improvement. Service providers were recruited through snowball sampling. Participants included current or former front-line service providers and managers in the children disability sector in Manitoba. Interviews followed a semi-structured interview guide with open ended questions and varied in length from 45 minutes to 90 minutes.

4. Recommendation Development

The Manitoba Advocate is empowered by law to make recommendations and monitor implementation with those recommendations (s. 11(1)(d), ACYA). Recommendations in this special report were informed by the child death investigation, data analysis, best practices reviews, key informant interviews, and stakeholder consultations.

A series of roundtables were organized to discuss preliminary findings in February 2021. The first roundtable was with MACY's Elder's Council, followed by a roundtable with senior representatives of the organizations reviewed, a meeting with First Nations and Metis government representatives, and a roundtable with caregivers.

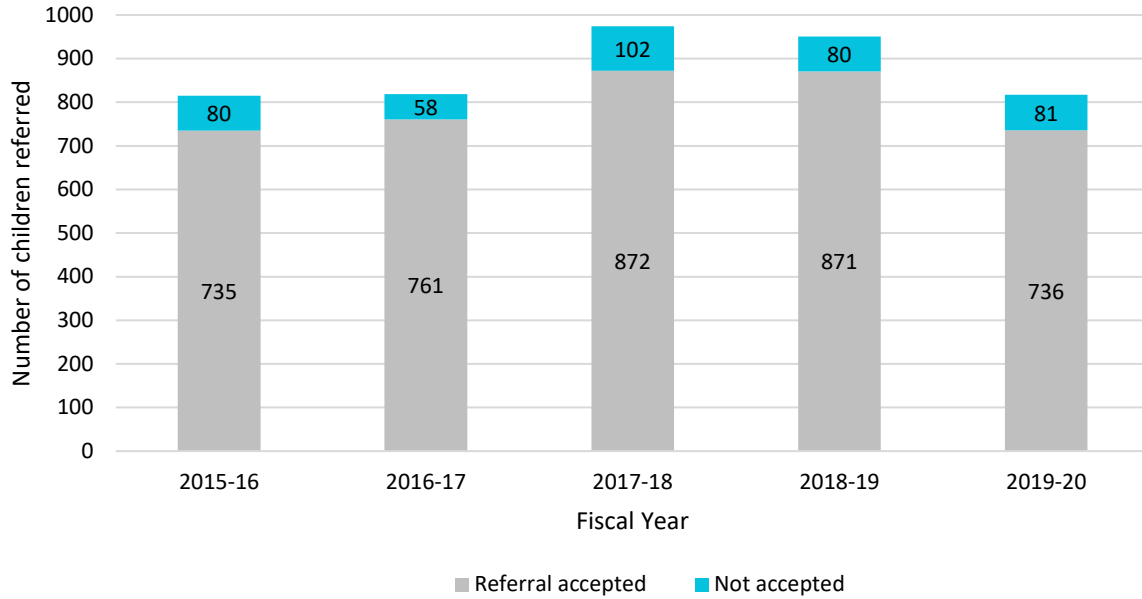
The purpose of stakeholder consultations was to ensure accuracy of information and interpretation and to provide the Manitoba Advocate with relevant information to consider when formulating recommendations to improve the effectiveness and responsiveness of services for children and youth living with disabilities in Manitoba.

APPENDIX D: DEMOGRAPHICS CAREGIVER'S SURVEY

Variable	N	%
Caregivers' relationship to the child		
Mother (biological, step, adoptive)	293	87.7
Father (biological, step, adoptive)	13	3.9
Foster Parent	17	5.1
Legal Guardian or other relative	11	3.3
Current age of the child		
birth-5 years	49	14.7
6-10 years	102	30.5
11-15 years	99	29.6
16-21 years	65	19.5
Not disclosed	19	5.7
Child's gender		
Female	97	29.0
Male	229	68.6
Non-binary or gender fluid	<6	0.9
Not disclosed	<6	1.5
Child's place of birth		
Canada	295	88.3
Outside Canada	29	8.7
Not disclosed	10	3.0
Child's Ancestry		
White	205	61.4
Indigenous (First Nation, Metis, or Inuit)	46	13.8
Indigenous and non-Indigenous	24	7.2
Black	13	3.9
Filipino	11	3.3
Other	18	4.9
Multiple	11	3.3
Not disclosed	7	2.1
Child in care of Child and Family Services		
No	300	89.8
Yes	23	6.9
Not disclosed	11	3.3
Health authority of child's residence		
Interlake-Eastern	15	4.5
Northern	8	2.4
Prairie Mountain	58	17.4
Southern	41	12.3
Winnipeg	146	43.7
Not disclosed	66	19.8

APPENDIX E: SUPPLEMENTAL RESULTS

Number of children referred and result of intake assessment (referral accepted versus referral not accepted) by fiscal year, 2015-16 to 2019-20



Referral accepted versus not-accepted by age, all referrals combined 2015-16 to 2019-20 fiscal years

