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Receipt of respite services among families of children and youth with special health care needs: A population-based cohort study

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Abstract

Objectives

Children and youth with special health care needs (CYSHCN) often require ongoing care, which can be an immense undertaking for their families. To provide a short-term break, families may obtain respite services, however, respite care may not be accessible or available to those who need it. The study objective was to identify demographic, socioeconomic, and health-related characteristics associated with receipt of respite services among families of CYSHCN in Manitoba.

Methods

Using a retrospective cohort design, a population-based cohort of CYSHCN (0 to 17 years old) (N=14,759) residing in Manitoba between 2013 and 2018 was defined using provincial-level administrative data (hospital, medical claims, education, disability services). Most of the cohort members (95.9%) were linked to their mother. We used multivariable logistic regression to determine the demographic, economic, and mental and physical health characteristics of the CYSHCN, their mothers, and siblings significantly associated with receipt of respite services. Additionally, the types of respite services received, and public funding dispersed for respite services during the study period were assessed.

Results

Less than one-quarter of families of CYSHCN (24.2%; 3,413) received at least one respite service. Among families who received respite, receipt was evenly distributed across neighbourhood-level income. However, the odds of receiving respite was lower in low income neighbourhoods (Q1: OR = 0.53, 95% CI [0.46, 0.61]; Q2: OR = 0.85, 95% CI [0.74, 0.98]). Of mothers in families that did not receive respite, 48.8% were diagnosed with a mental health disorder, and 60.8% had a physical health condition. Receipt of respite services was significantly associated with mothers' age (OR=1.05, 95% CI [1.04, 1.05]) and marital status (OR=1.71, 95% CI [1.57, 1.86]). Half (52.0%; 14,190) of all respite service records were attributed to self-managed services.

Conclusions

Many families of CYSHCN in Manitoba are not receiving publicly funded respite services. Our results suggest there are inequities in these services as respite was lower among families residing in economically disadvantaged neighbourhoods. Caring for a CYSHCN and accessing respite services (or not) may affect mothers' mental and physical health, particularly for families doing self-managed respite. Efforts and policy review are needed to address the limited and inequitable receipt of respite services for Manitoba families of CYSHCN.

Keywords

children and youth with special health care needs; families; respite services; administrative data; population-based

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Introduction

Children and youth with special health care needs (CYSHCN) include infants, children, and youth who have one or more chronic physical, developmental, behavioral, or emotional conditions, and require special health and support services. CYSHCN often also live with mental disorders (e.g., anxiety, depression, attention deficit hyperactivity disorder, obsessive–compulsive disorder) [1, 2]. This unique population requires ongoing care, monitoring and support [3, 4], which can be an immense undertaking for caregivers (parents and siblings) of CYSHCN, that involves constant vigilance and the coordination of multiple needs, relationships and services in a complex system with limited community-based supports. Additionally, these responsibilities often require substantial financial, physical, social and emotional resources which can take a toll on families and impact family functioning [5, 6]. For example, siblings who support the caregiving can experience mental health challenges [7, 8], and parents, as primary caregivers, may experience sleep deprivation, depression [9, 10], or have unique social and relational needs [11, 12], adding to the complexity of their daily lives [13].

Respite care, which is alternative care for persons with disabilities, can support families of CYSHCN and CYSHCN themselves by providing them with short breaks in-home or out-of-home (depending on needs, resources, and eligibility) [14–18]. Respite is a key component in a family-centred care approach [19], as it reduces stress, anxiety and depression [20], and increases independence and functioning in caregivers and the CYSHCN [18, 21, 22].

In Manitoba, Canada, the provincially funded and administered Children's disABILITY Services (CDS) program provides respite to families who are caring for a child under age 18 who have specific conditions (e.g., intellectual disability, developmental delay, autism spectrum disorder, lifelong physical disability, or high probability of developmental delay due to a pre-existing condition). Accessing publicly funded respite services (CDS) requires a physician-diagnosed disability that meets CDS criteria. Referrals are accepted by CDS for children under 18 years of age from families (self-referral), health professionals, daycares, or schools.[23] In this province, publicly funded respite can be provided in or out of the child's home by CDS-selected agency staff, or via Self-Managed respite, where families hire their own workers and are reimbursed by CDS. Additional services and supports provided to eligible Manitoba families by CDS include After School Care and Summer Gap, intended to capture respite needs outside of school hours and during summer break, respectively [24]. Unfortunately, in Manitoba as in other jurisdictions, access to publicly funded respite is not universal. Often families experience availability and accessibility challenges coupled with inadequate funding [25–30].

Objectives

To date, few population-based studies have examined inequities in respite care maintenance using linked administrative data. A population-based approach using linked administrative data is a robust method as the same individuals and their family members can be tracked over time across various services [31, 32], allowing for the identification of family member outcomes (e.g., siblings) [33], and gaps and inequities in the receipt of respite care.

This study, which is a part of a larger mixed methods study [30, 34], sought to determine the sociodemographic and health characteristics associated with receipt of respite services. We used receipt as a proxy for access. We hypothesized that respite care is not accessible and equitably distributed to all Manitoba families of CYSHCN. The data only reflects respite services received from and funded through the publicly funded provincial government disability services programs and does not include private respite services paid for out-of-pocket by families.

Methods

Data sources

This study used administrative data in the Manitoba Population Research Data Repository ('the Repository') at the Manitoba Centre for Health Policy (MCHP) [35]. Although administrative datasets for research exist in other jurisdictions across Canada, the Repository in Manitoba holds among the most comprehensive set of administrative databases in the country, which includes individual-level linkable, de-identified records of all Manitoba residents using their Personal Health Information Number (PHIN). Unique in North America, the Repository at MCHP has capabilities to link individuals across several generations with their social, health, education, and justice data [36]. To receive health services, most individuals in Manitoba have a Personal Health Information Number (PHIN) that can be encrypted and used to link deterministically across datasets for research purposes. Permission must be obtained by researchers to access and use the databases, which are owned and governed by various provincial government departments. There are strict measures in place to protect the data. The data in the databases are collected for administrative reasons (e.g., physician remuneration); however, the utility and validity of the data has been previously documented and used extensively used for research purposes [37, 38]. Individuals' data were linked across the data sources. Given that less than 5% of our sample was missing from our analyses, we did not attempt to adjust or impute the missing data. This small of amount of missing data is unlikely to bias the results.

Cohorts

First, we created a population-based cohort of children aged 0 to 17 years who were diagnosed with a special health care need (see Figure 1) and resided in Manitoba at any point during the 5-year study period, April 1, 2013, to March 31, 2018. The following databases were used to identify CYSHCN diagnoses (see Supplementary Table for CYSHCN Disability Definitions), receipt of Special Education funding and or publicly funded respite services:

- Health (i.e., Hospital Abstracts, Medical Claims/Medical Services, Drug Program Information Network)
- Manitoba Education Special Needs Funding
- Children's disABILITY Services (CDS) (for ages 0 to 17 years)

- Community Living disABILITY Services (CLDS) (for ages 18 years and older)

The disability conditions and their corresponding International Classification of Diseases (ICD) codes were selected based on previous work conducted by researchers at the Manitoba Centre for Health Policy, as defined in the "Mental Health of Manitoba's Children" report [39], and according to eligibility criteria for Manitoba Education Special Needs Funding Criteria Level 2 (moderate to severe impairment) and Level 3 (profound impairment) used in the "How are Manitoba's Children Doing?" report [40]. The study cohort consisted of 14,759 children (Figure 1). Residence in Manitoba was based on six-digit postal codes in the Manitoba Health Insurance Registry ("Registry"), a population-based registry maintained by the provincial health department. Children who met at least one study criterion (physician diagnosis of a developmental disability, spina bifida, or cerebral palsy, received special education funding, or received publicly funded respite services from CDS/CLDS) were included in the study (see Figure 1). The CLDS dataset includes all CYSHCN who turned 18 years of age at some point during the fiscal year (April 1-March 31), therefore some CYSHCN in the CLDS database would still be 17 years of age during a given fiscal year. Children who met multiple criteria were only included once for cohort development.

Next, we created a population-based cohort of mothers by linking children's birth records to their mothers using the Registry (mothers can be identified with a greater degree of certainty than fathers) [40]. Almost all CYSHCN (N = 14,530, 98.5%) were linked to their mother's health card number; 14,127 mothers were identified. Given that less than 5% of our sample was missing from our analyses, we did not attempt to adjust or impute the missing data. This small among of missing data is unlikely to bias the results. Finally, we created a sibling cohort from birth records linking the mothers' records to her other children; 33,719 siblings were identified. Biological children were identified through their mother's PHIN, and stepchildren and children adopted at birth were identified through the family registration number, which is connected to the family head (usually the father). The unit of analysis was the family (N = 14,127), which is the number of mothers, as mothers were the head of the household and defined the unit of analysis.

Study variables

The Charlson Comorbidity Index (CCI) is based on 17 medical comorbid conditions[43] identified from ICD-9-CM and ICD-10 coding algorithms in hospital abstracts and medical services data [44–46]. Each comorbidity has an associated weight from one to six based on mortality risk, with the sum of weights resulting in a singular comorbidity score [44, 47]. The CCI scores of zero to six reflect the range of comorbidities; higher scores predict higher mortality risk [48] and higher resource use [44, 47, 49]. The CCI has been validated [44, 47] and used in population-based research [50, 51], and has also been used with pediatric samples to predict illness severity, mortality, and the need for hospitalization for patients with COVID-19 [52–54]. While there are pediatric-specific comorbidity measures (e.g. pediatric comorbidity index) [55], the CCI was available to us through the MCHP at the time of analysis and is a stronger predictor of mortality in pediatric populations than physical health indicators.

Receipt of provincially funded respite services was defined as the number of respite services plans, recorded as 'respite service records' (e.g., Respite>Regular Hours/Service, or Self-Managed>Respite) approved for the CYSHCN cohort and their families and delivered to them during the study period. A respite service plan is based on a needs assessment conducted by CDS/CLDS program staff. Respite service plans vary in duration (e.g., 2 months to 12 months), after which needs are assessed and a new respite service plan is created and approved. The study variables are presented in Table 1.

Statistical analysis

Chi-square and independent t-tests were performed to test for statistically significant differences ($p < 0.05$) between those who received respite services and those who did not. Next, we used multivariable logistic regression to examine factors associated with receipt of respite services. Variables were selected a priori from the literature and by conceptual relevance. Additionally, variables were partly included based on the bivariate associations. Variables were sequentially entered in blocks (child, maternal, household) and the models were compared using the Bayesian Information Criterion (BIC). Odds ratios and 95% confidence intervals were calculated. Lastly, we calculated descriptive statistics to summarize receipt of funded respite services. Analyses were conducted using SAS v 9.4.

This study was approved by the Health Research Ethics Board at the University of Manitoba (#H2019:106) and the Health Information Privacy Committee of the Government of Manitoba (File No.2019/20-01).

Results

Receipt of respite services by the characteristics of the cohort

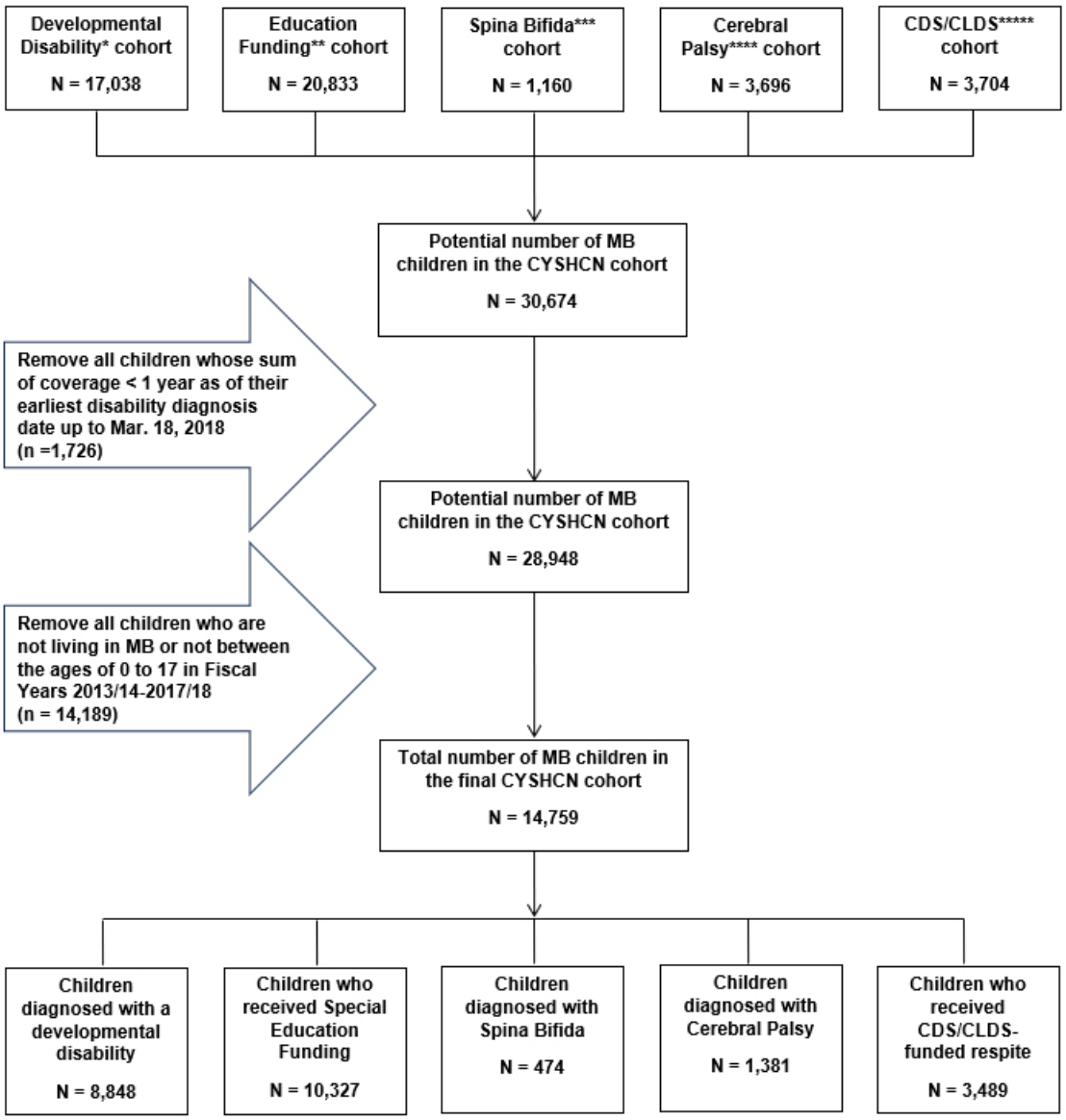
Descriptive statistics

Less than one quarter of the families (24.2%) received at least one respite service during the study period. The majority (71.5%) of the CYSHCN were male. At the end of the study period, the CYSHCN were on average 13.7 years old (SD = 5.14) (respite, M = 13.25 years, SD = 4.68; did not receive respite, M = 13.80 years, SD = 5.27) and the mothers were on average 41.73 years old (SD = 7.67) (respite, M = 42.99, SD = y7.47; did not receive respite, M = 41.33, SD = 7.69). Slightly more than one-third (36.0%) of the mothers were married. The average number of children per family was 2.42 (SD = 2.03).

Overall, 41.6% and 27.2% of the CYSHCN had a physician-diagnosed mental and physical health condition, respectively, and 30.6% had one or more CCIs. Among the mothers, 47.5% had a mental health condition, 59.2% had a physical health condition, and 45.4% had at least one CCI.

We also examined several family-level variables. Overall, more than half of the CYSHCN (57.1%) resided in an urban area. There is an income gradient, such that there was a higher

Figure 1: Flow chart for the child and youth with special health care needs cohort development



NOTE: The CYSHCN definition includes the following cohorts of children:
*Developmental Disability cohort: Total number of children diagnosed between Apr.1,1984-Mar.31,2018 aged 0 to 17 years.
**Special Needs Education cohort (Autism Spectrum Disorder, hearing or vision impairment, and emotional/behavioural disorder): Total number of children that received level II or III funding (based on need level) during academic year 1995/96- 2017/18 aged 4 to 17 years.
***Spina Bifida cohort: Total number of children diagnosed between Apr.1,1984-Mar.31,2018 aged 0 to 17 years.
****Cerebral Palsy cohort: Total number of children diagnosed between Apr.1,1984-Mar.31,2018 aged 0 to 17 years.
*****Children's disABILITY Services (CDS)/Community Living disABILITY Services (CLDS) cohort (intellectual disability, developmental delay, autism spectrum disorder (ASD), a life-long physical disability, or a high probability of developmental delay): Total number of children that received respite services between Apr.1,2013-Mar.31,2018 aged 0 to 17 years.

proportion in the lower income quintiles (Q1, 28.2%; Q2, 18.9%) and a lower proportion in the higher income quintiles (Q4, 16.2%; Q5, 13.5%). Overall, 61.6% of the CYSHCN had a family member who received income assistance and 12.8% resided in public housing.

Bivariate comparisons

The characteristics of the group that received respite and the group that did not receive respite are compared in Table 2. The CYSHCN groups were similar with respect to the sex distribution ($\chi(1)^2 = 0.73$, $p = 0.3938$). Mothers who did not receive respite had on average more children (i.e. more siblings) (M = 2.60, SD = 2.13) (M difference = 0.78, SD difference = 2.00; $t(14125) = 19.68$, $p < 0.001$) and were less likely to be married (31.9%) ($\chi(1)^2 = 329.05$, $p < 0.001$) than mothers who received respite (children: M = 1.83, SD = 1.51; married, 49.0%).

The CYSHCN groups did not differ significantly with respect to having physician-diagnosed mental ($\chi(1)^2 = 3.42$,

Table 1: Study variables

Study Variable	Database Source
Sex, marital status, and region of residence[§]	Manitoba Health Insurance Registry
Deaths	Vital Statistics
Income quintile (IQ)[¶]	2016 Canadian Census
Receipt of income assistance (yes/no)	Social Allowances Management Information Network
Residence in public housing (yes/no)	Tenant Management System
Mental disorder diagnoses[†]	Hospital Abstracts, Medical Claims/Medical Services, and Drug Program Information Network
Physical health diagnoses[‡]	Hospital Abstracts, Medical Claims/Medical Services, and Drug Program Information Network
The Charlson Comorbidity Index (CCI)[#]	Hospital Abstracts, Medical Services
Receipt of provincially funded respite services (yes/no), the type of respite services[**]	Children's disABILITY Services, the Community Living disABILITY Services, and Plans Paid

§Postal codes were aggregated to different geographical scales (e.g., Regional Health Authority, rural/urban).
¶An area-level measure of household income (Q1 – lowest, Q5 – wealthiest); defined according to where people were first residing in the study period.
†Mood and anxiety disorders, substance use disorders, psychotic disorders (including schizophrenia), Attention Deficit Hyperactivity Disorder, conduct disorder, and personality disorders for mothers were based on validated definitions [39, 41].
‡Physical health conditions included asthma, diabetes, plus hypertension for mothers; these are some of the most common chronic conditions among Manitoba children [39, 40] and adults [42].
#The Charlson Comorbidity Index (CCI) was used to categorize diagnosed comorbidities.
**As per Manitoba Department of Families (17), and invoiced payout amounts.

$p = 0.0645$) or physical ($\chi(1)^2 = 0.01$, $p = 0.9295$) health conditions but differed with respect to CCI scores ($\chi(3)^2 = 88.61$, $p < 0.0001$). Specifically, the proportion with one or more CCIs was higher in the group that received respite. Mothers who received respite services were significantly less likely to have a physician-diagnosed mental health (43.5% vs 48.8%; $\chi(1)^2 = 30.17$, $p < 0.0001$) and/or physical health condition (54.2% vs 60.8%; $\chi(1)^2 = 46.60$, $p < 0.0001$) and had significantly fewer CCIs than mothers who did not receive respite services (0 CCIs: 58.4% vs 53.4%; $\chi(3)^2 = 41.19$, $p < 0.0001$).

The respite-receiving group (62.2%) was significantly more likely to reside in an urban centre than the group that did not receive respite (55.4%) ($\chi(1)^2 = 48.44$, $p < 0.001$). Income was significantly associated with receipt of respite services ($\chi(5)^2 = 559.95$, $p < 0.001$). There was an income gradient for the group who did not receive respite; that is, they tended to reside in lower income areas (31.1% in Q1 vs 11.8% in Q5). In contrast, children who received respite services were approximately equally distributed across the income quintiles (approximately 20% in each). Respite-receiving children were significantly more likely to have a family member who received income assistance (34.7% vs 30.6%; $\chi(1)^2 = 20.09$, $p < 0.001$) but were significantly less likely to reside in public housing (11.6% vs 13.2%; $\chi(1)^2 = 6.03$, $p = 0.0141$) than the group who did not receive respite services.

Multivariable model results

Next, we used multivariable logistic regression to determine the child, mother, and family characteristics significantly associated with receipt of respite services. The CYSHCN-only model had the highest BIC (15,595.5363). Adding the maternal variables reduced the BIC (15,111.9675) and the model with the CYSHCN and household variables also improved fit (BIC = 14,701.5402). The full model, which included CYSHCN, maternal, and household variables, produced the lowest BIC (BIC = 14,380.3225). Sequential likelihood ratio tests indicated that adding maternal variables significantly improved fit over the child model (Δ-2LL = 550.46, df = 9, $p < 0.0001$) and adding household variables (Δ-2LL = 980.00, df = 7, $p < 0.0001$) also improved model fit. The full model showed an additional improvement (Δ-2LL = 388.11, df = 7, $p < 0.0001$) (i.e., comparison between the child and household model with the full model). Accordingly, the full model was retained as the best fitting model. The results are presented in Table 3.

Sex of the CYSHCN was not significantly associated receipt of respite (OR = 0.99, 95% CI = 0.90, 1.08), whereas age was negatively associated with receipt of respite (OR = 0.94, 95% CI = 0.93, 0.95). Unlike the results of the bi-variate analyses, CYSHCN who had a physician-diagnosed mental health condition had a significantly higher odds of receiving respite services than CYSHCN who did not have a mental health condition (OR = 1.18, 95% CI = 1.08, 1.28). For the CYSHCN, the odds of receiving respite increased as the CCIs increased (2 CCIs: OR = 1.68, 95% CI = 1.43, 1.98; 3+ CCIs: OR = 1.69, 95% CI = 1.43, 2.00).

The odds of receiving respite were higher for mothers who were married (OR = 1.71, 95% CI = 1.57, 1.86). Mothers' age was significantly related to receipt of respite (OR = 1.05, 95% CI = 1.04, 1.05). Unlike the results of the bi-variate analyses, mothers' mental health (OR = 1.01, 95% CI = 0.92, 1.10) and physical health (OR = 0.92, 95% CI = 0.83, 1.01) were not significantly related to receipt of respite. Mothers who had 3+ CCIs had a significantly lower odds of receiving respite

Table 2: Characteristics of the families (N = 14,147) who received respite versus did not receive respite

Level	Variable	Category	Received Respite Care				*p*-value
			Yes (N = 3413)		No (N = 10714)		
			n	%	n	%	
Child	Sex	Male	2421	70.9	7681	71.7	0.3938
		Female	992	29.1	3033	28.3	
	Any Mental Health Diagnosis[§]	Yes	1373	40.2	4502	42.0	0.0645
		No	2040	59.8	6212	58.0	
	Any Physical Health Diagnosis[+]	Yes	929	27.2	2908	27.1	0.9295
		No	2484	72.8	7806	72.9	
	CCI	0	2208	64.7	7595	70.9	<0.0001
		1	655	19.2	2013	18.8	
		2	275	8.1	554	5.2	
		3+	275	8.1	552	5.2	
Mother	Married	Yes	1672	49.0	3415	31.9	<0.0001
		No	1741	51.0	7299	68.1	
	Any Mental Health Diagnosis[§]	Yes	1483	43.5	5233	48.8	<0.0001
		No	1930	56.5	5481	51.2	
	Any Physical Health Diagnosis[+]	Yes	1850	54.2	6514	60.8	<0.0001
		No	1563	45.8	4200	39.2	
	CCI	0	1992	58.4	5716	53.4	<0.0001
		1	734	21.5	2379	22.2	
		2	207	6.1	642	6.0	
		3+	480	14.1	1977	18.5	
Household	Income Quintile	NF	8	0.2	841	7.8	<0.0001
		Q1	655	19.2	3329	31.1	
		Q2	713	20.9	1951	18.2	
		Q3	736	21.6	1698	15.8	
		Q4	659	19.3	1635	15.3	
		Q5	642	18.8	1260	11.8	
	Income Assistance	Yes	1183	34.7	3275	30.6	<0.0001
		No	2230	65.3	7439	69.4	
	Public housing	Yes	396	11.6	1416	13.2	0.0141
		No	3017	88.4	9298	86.8	
	Region	Urban	2123	62.2	5939	55.4	<0.0001
		Not urban	1290	37.8	4775	44.6	

Notes.
[§] includes mood and anxiety disorders, substance use disorders, psychotic disorders (including schizophrenia), attention deficit hyperactivity disorder, conduct disorder, plus personality disorder for mothers.
[+] includes asthma, diabetes, plus hypertension for mothers.

(OR = 0.80, 95% CI = 0.70, 0.91) relative to mothers who had 0 CCIs.

Regarding the family-level characteristics, income quintile and income assistance were significantly related to receipt of respite while residing in public housing (OR = 1.02, 95% CI = 0.89, 1.17) and region of residence (OR = 0.98, 95% CI = 0.89, 1.06) were not significantly related. Specifically, families who received income assistance had a significantly higher odds of receiving respite than families who did not receive respite (OR = 1.97, 95% CI = 1.78, 2.19). Receipt of respite decreased as income quintile increased, with significantly lower odds for Q1 (OR = 0.53, 95% = 0.46, 0.61) and Q2 (OR = 0.85, 95% CI = 0.74, 0.98). The odds of receiving respite decreased as the number of siblings increased (OR = 0.84, 95% CI = 0.82, 0.86).

Type of respite services received by manitoba families of CYSHCN

In total, there were 27,308 respite service/program records (respite services plans) attributed to 3,489 children, meaning these CYSHCN received one or more respite services/programs during the study period (Table 4 Respite program/services and sub-services provided). Among the respite services/programs received, half (52.0%; 14,190) were for self-managed services (respite and summer gap-programming to support CYSHCN

Table 3: Adjusted odds ratios and 95% confidence intervals for receipt of respite services

Level	Variable	Category	OR (95% CI)
Child	Sex	Male	0.99 (0.90, 1.08)
		Female	Ref
	Any Mental Health Diagnosis	Yes	**1.18 (1.08, 1.28)**
		No	Ref
	Any Physical Health Diagnosis	Yes	1.01 (0.90, 1.12)
		No	Ref
	CCI	1	1.06 (0.94, 1.20)
		2	**1.68 (1.43, 1.98)**
		3+	**1.69 (1.43, 2.00)**
		0	Ref
	Age		**0.94 (0.93, 0.95)**
Mom	Married	Yes	**1.71 (1.57, 1.86)**
		No	Ref
	Any Mental Health Diagnosis	Yes	1.01 (0.92, 1.10)
		No	Ref
	Any Physical Health Diagnosis	Yes	0.92 (0.83, 1.01)
		No	Ref
	CCI	1	0.95 (0.85, 1.06)
		2	1.01 (0.84, 1.20)
		3+	**0.80 (0.70, 0.91)**
		0	Ref
	Age		**1.05 (1.04, 1.05)**
Household	Income Quintile	NF	**0.04 (0.02, 0.08)**
		Q1	**0.53 (0.46, 0.61)**
		Q2	**0.85 (0.74, 0.98)**
		Q3	0.96 (0.84, 1.10)
		Q4	0.92 (0.80, 1.06)
		Q5	Ref
	Income Assistance	Yes	**1.97 (1.78, 2.19)**
		No	Ref
	Public housing	Yes	1.02 (0.89, 1.17)
		No	Ref
	Region	Urban	0.98 (0.89, 1.06)
		Not urban	Ref
	Number of siblings		**0.84 (0.82, 0.86)**

Note. Bolded values denote statistical significance at $p < 0.05$.

to maintain skills), while less than one quarter (22.3%; 6,090) were attributed to provincial department or regional health authority staff delivery (regular hours/service, nursing (funded)).

Of the 27,308 respite services records, 27,093 (99.2%) were linked to a mother. Overall (out of 27,093 records), 67.2% of the records were associated with a mother who had a diagnosed mental disorder and/or physical health condition, although the percentage varied by sub-service (as shown in Table 4).

To assist in identifying inequities in availability, accessibility, and affordability, we explored public (government) spending on respite services in Manitoba (Table 5). Approximately half of the total spending was allocated to self-managed (respite, summer gap) care, which is independently arranged and managed by families. The costliest sub-services were support staff for afterschool care, self-managed respite, and overnight respite.

Discussion

Key findings

To the best of our knowledge, this is the first population-based cohort study using linked administrative data to examine characteristics of families of CYSHCN relative to receipt of publicly funded respite care. A key finding is that less than one-quarter of Manitoba CYSHCN (24.2%) received at least one respite service. Furthermore, we demonstrated that there are marked economic differences in receipt of respite in this province as non-receipt of respite was more likely among those

Table 4: Respite program/services and sub-services provided during the 5-Year study period

Program	Service	Sub-Service	# respite service records†	% total respite service records	Mother mental disorder and/or physical health diagnosis	
					N	%
Children's disABILITY Services (CDS) (ages 0 to 17 years)	After School Care	Support Staff	1,346	4.9	888	66.0
	Respite	Regular Hours/Service	6,071	22.2	4,166	68.6
		Agency Delivered	1,406	5.2	1,087	77.3
		Associated Expenses	157	0.6	113	72.0
		Out of Home – Overnight	65	0.2	25	38.5
		Nursing (Funded)	19	0.1	19	100.0
	Self Managed	Respite	12,165	44.6	7,921	65.1
		Summer Gap	2,025	7.4	1,350	66.7
	Summer Gap	Support Staff	3,562	13.0	2,355	66.1
Community Living disABILITY Services (CLDS) (ages 18 years and older)	Respite	Agency Delivered	368	1.4	224	60.9
		Out of Home – Overnight	22	0.1	16	72.7

Table 5: Total public funds ($CAD) spent by sub-service over the 5-year study period over all individual CYSHCN

Service	Sub-Service	# of individual CYSHCN provided sub-service	5-year Sums Sums of Annual Total Spent	5-year Average of Annual Spent	5-year Median of Annual Spent
Respite	Regular Hours/Service	1,247	8,641,454.49	6,929.80	3,315.80
	Out of Home – Overnight	21	210,017.07	10,000.81	6,684.00
	Nursing (Funded)	*s*	33,282.80	8,320.70	7,923.67
	Agency Delivered	294	2,583,095.45	8,786.04	4,802.28
After School Care	Support Staff	243	3,363,627.18	13,842.09	10,118.35
Summer Gap	Support Staff	1,289	3,238,688.47	2,512.56	1,568.78
Self-Managed	Respite	1,882	20,787,517.38	11,045.44	7,215.50
	Summer Gap	741	2,302,945.88	3,107.89	1,920.00
TOTAL		**5,717**	**41,160,628.72**	**64,545.33**	**43,548.38**

Note. s means the data were suppressed due to <5.

residing in lower-income neighbourhoods. Given the major role parents play in providing care for their CYSHCN, our finding that receipt of respite services was significantly associated with mothers' age and marital status, and that approximately half of mothers in the total sample had a physician diagnosed mental health and physical health conditions is noteworthy. Finally, half of all respite service records were attributed to self-managed services, meaning that respite services were arranged and managed by families of CYSHCN.

Comparison with prior literature

Limited receipt of respite

Our finding that only 24.2% (3,413) of 14,147 families with CYSHCN received at least one respite service during the study period (2013-14 to 2017-18) supports qualitative research within the Manitoba respite services context[11, 12, 56] citing low to moderate receipt respite care for families with CYSHCN. Further, research from the Manitoba Advocate for Children and Youth (MACY) reported that in the years 2015-16, 2016-17, and 2017-18, 37.7%, 35.4%, and 33.6% of Manitoba families respectively, received publicly funded respite [57]. These Manitoba rates are lower than those reported in research from other Canadian jurisdictions. For instance, in Ontario studies, 49.5% of families with CYSHCN had received respite, and 46% of caregivers of children with cerebral palsy used formal respite care services in the past 12 months [17, 58]. In British Columbia, 53% of families of CYSHCN had access to publicly funded respite care [59]. These differences from Manitoba findings could be due to varying

eligibility requirements or respite services availability in these provinces [60]. Other reasons for differences may be due to the type of research method used (e.g., voluntary questionnaire versus administrative data), types of diagnoses included, or to declining public funding for respite services in Manitoba as noted in the MACY report [57]. Nonetheless, our findings reinforce the need to address and further examine limited respite care services for families of CYSHCN in Manitoba.

Younger children get respite

To determine where the greatest gaps in service provision occur, we examined receipt by the characteristics of CYSHCN, their mothers, and the family. The findings suggest that respite services are delivered to families with younger CYSHCN and those CYSHCN who have a physician-diagnosed mental disorder, and greater number of physical health conditions. This is based on the finding that age, mental health, and the CCI scores were strongly associated with receipt of respite services for CYSHCN. As the CYSHCN aged, they had a decreased odds of receiving respite services, and CYSHCN with a mental health diagnosis and higher CCI scores had higher odds of receiving respite services.

Regarding younger age and receipt of respite, during pre-school age (0-5 years), parents may notice developmental delays and seek and receive a diagnosis for their child [61], and younger CYSHCN may be attending daycare or pre-school which may increase referrals to CDS for respite. Further, previous population-based research from the U.S. reports that CYSHCN who were less than six years old were three times as likely and those 6 to 11 years old were two times as likely to require respite than children who were 12 to 17 years of age [62]. As CYSHCN age, it is possible that their conditions improve, and thus they require less respite care, which may partly explain our findings of decreased odds of respite receipt . It also stands to reason that children with mental health and more physical health diagnoses would be more likely to receive respite services as CYSHCN are at increased risk for mental and physical health conditions [63].

Mother characteristics and respite receipt

Mothers' age, marital status, and number of children were significantly associated with receipt of respite services. Specifically, mothers who were married and older had a higher odds of receiving respite than those who were younger and not married, and mothers with more children (number of siblings) had a lower odds of receiving respite. with marital status ($\chi^2 = 7.796$, $P = 0.099$), caregiver age ($t = 1.550$, $P = 0.122$), or number of children in household ($t = 4.090$, $P = 0.129$) [17].

We found that mothers who were married were more likely to be in families receiving respite. One possible explanation is that these mothers may have been in dual income households with sufficient economic resources to use self-managed respite, which requires families to pay out of pocket and later seek reimbursement from CDS; notably, as half of all respite service records were for self-managed services. For example, Dyches et al. [64] found that single parents in the U.S., especially mothers of children with ASD, experienced greater economic disadvantage than married couples, with only 13.7% (n = 122) accessing formal respite. If similar patterns hold in the current study context, the combination of economic disadvantage among single mothers and CDS's encouragement for self-managed respite in Manitoba may help explain why married mothers were more likely to receive respite services. Further research is required to determine reasons for these differences.

Mothers' health and respite

CYSHCN's mothers' mental health, physical health, and their CCI scores were initially significantly associated with receipt of respite. However, they became insignificant when the other characteristics were accounted for. Nonetheless, we note that of the non-respite receiving group in the current study, the percentage of mothers with a physician diagnosed mental health (48.8%) or physical health conditions (60.8%) is concerning, both for themselves as individuals and for their role as a caregiver. Mothers, particularly those with health conditions, may struggle to meet their own needs and the needs of their children, potentially contributing to worsening mental and physical health and increased hospitalizations for their child(ren) and themselves [65]. We concur with previous recommendations to more actively attend to the mental health of mothers [66] and parents [67] of CYSHCN to support the wellbeing of families.

Lower income and non-receipt of respite

Study findings suggest there may be inequity in the receipt of respite services with respect to economic status given that families residing in the lowest income areas (e.g., Income Quintile Q1) had a significantly lower odds (OR = 0.53, 95% CI [0.46, 0.61]) of receiving respite than families residing in higher income areas. Therefore, it appears there may be substantial unmet need for respite services among Manitoba families of CYSHCN who reside in economically disadvantaged neighbourhoods, which is supported by the literature [68]. However, the CYSHCN group who received respite were more likely to have a family member who received income assistance (OR = 1.97, 95% CI [1.78, 2.19]) compared to those who did not receive respite. This may be reflecting that families that receive respite are more connected to supports in general than families that did not receive respite. Access to formal services of any kind for marginalized families, including young and sole parent families, low income, Indigenous and culturally diverse families is often barriered, and engagement with services can be limited [69]. This can be due to families not being heard, services being inflexible or inattentive to their needs, and lack of trust in service providers [70]. We also acknowledge that families with lower socioeconomic status may face barriers in access to medical care, disability diagnoses and respite care services, which may have influenced our results [64, 71–73].

Urban/Rural differences

Initially, it appeared that access to respite services may be better in urban areas; however, region of residence was not significantly associated with receipt of respite services once the other characteristics were accounted for. Thus, access to respite services is not necessarily better in/close to urban centres and worse in the north. This conflicts with regional disparities in receipt of respite noted in other jurisdictions

(e.g., Ireland [74] and Alberta, Canada [75]). Further research is needed to understand this discrepancy.

Type of respite services

Half (52.0%; 14,190) of all respite service records were attributed to self-managed services, meaning that respite services were arranged and managed by families. Although directly comparable literature is sparse, an environmental scan of direct funding home care programs for all ages (includes home care, individualized funding, and respite) operating in 2017-18 across Canada reported that approximately 25% of Manitoba clients of the provincially funded Self and Family Managed Care program acted as self-managers, typically for younger adults with disabilities [76]. Our finding that half of Manitoba families of CYSHCN use self-managed respite could be due to a CDS policy that encourages families to self-manage their respite needs [77]. Additionally, about two-thirds of the mothers who provided self-managed care had a physical health and/or mental disorder diagnosis. Notably, in previous research, self-management policy design has been discouraged as it may impede those with compromised decision-making capacity or people of lower socioeconomic status [78]. Further research on the impact of self-managed respite care on families of CYSHCN is needed to evaluate the merits and deficiencies of self-managed care policy.

Implications for Public Health and Policy

Respite services can and do play a key role in the wellbeing of families of CYSHCN [6, 15] by "strengthening sibling, parent, and overall family functioning [and] ... improve[ing] family members' ability to cope with and meet the needs of the person with a disability" [79, p. 481]. Based on our study findings, along with evidence from Canadian families and respite services providers [30, 34], it appears many Manitoba families may not be receiving publicly funded respite care, and may not be receiving any respite if they are not able to finance private or self-managed respite themselves. The call for a health system response to the respite needs of CYSHCN and their 'all-too-often exhausted' networks of parents. . . ' [80, p. 2] and 'fragile' families [81] has been made previously. This is especially important given the neighbourhood income disparities related to receipt of respite found in our study. Universal and targeted approaches [82] that engage multiple sectors (e.g., health, social services) and different levels of government are needed to address gaps in respite services to ensure equitable access and receipt of publicly funded respite for all CYSHCN in Manitoba, particularly for lower economic status families.

The physical and mental health of caregivers of CYSHCN is a priority given the complex care requirements for CYSHCN [3], which can be taxing for families [6, 7], particularly for mothers who are often the primary caregivers [83, 84]. The high rates of maternal mental and physical health diagnoses in our study sample, coupled with the Manitoba CDS trend toward self-managed respite care, points to the need for program and policy improvements that address the needs of the whole person, through family-centred [85], coordinated [86] and collaborative care across health and social care sectors.

Strengths and limitations

The use of linked administrative data to assess receipt of respite among Manitoba families of CYSHCN enabled a broad assessment of family characteristics relative to respite services and provided new and valuable insights into potential gaps in respite services for this population. The benefits of this methodology are noteworthy, including objective measures (i.e., ones not based on recall), continuous data collection, and analysis of long-term outcomes [37, 87].

Study findings however are not without limitations. Regarding the administrative data, we only had access to records of respite provided by publicly funded services, thus data do not include private respite services received through out-of-pocket funding by families. Therefore, there may be families in the group that did not receive publicly funded respite but that did receive private respite services. We could also not account for the number of respite hours provided to families. The respite services data is not well-collected, documented, completed, or intuitive to interpret. Additionally, the datasets we used do not include racial, ethnic, or cultural identity; thus, we were not able to examine the impact of intersecting identities on receipt of respite services. Income quintiles may be less accurate for rural areas [82] as the MCHP uses different cut-offs to determine urban and rural income quintiles because of differences in income distribution and population density [88]. Health diagnoses only reflect those who sought treatment from physicians, as the MCHP administrative data does not capture therapy and counseling received from psychologists and other mental health professionals. We also did not account for the timing of mothers' health diagnoses with respect to when respite was received.

While we strived for a whole-family approach, fathers were not included due to the uncertainty in linking children to their fathers [40]. If a CYSHCN could not be linked to their mother, their mother and siblings were not included; thus, the cohorts are incomplete. We also did not verify that the CYSHCN and their mother lived in the same household. This has implications for the geographic and income-related findings.

Finally, the use of the CCI may have influenced our findings, as it is not ideal for pediatric populations; pediatric-specific comorbidity measures (e.g. pediatric comorbidity index) may provide more appropriate assessments [55].

Future directions

This study provides a basis for further research. This could include examining family socioeconomic and health characteristics by CYSHCN disability type and by the number of disabilities, which may help to clarify the burden of care experienced by families. In particular, the connection we found between non-receipt of respite and poor physical and mental health of mothers of CYSHCN warrants further attention. Additionally, examining the characteristics of families of CYSHCN based on the number of respite service records or plans by disability could provide insight on the level of respite services accessed by Manitoba families and inform future care planning and policy. Further, alternative analytic approaches (e.g. CART analysis) could be useful for identifying and visualizing the health and sociodemographic characteristics

most strongly associated with not receiving respite services. Finally, an economic analysis could determine whether the costs of providing publicly funded respite services to families of CYSHCN are offset by savings in the Manitoba healthcare system, thereby providing a rationale for increasing funding for respite services.

Conclusion

This is the first population-based cohort study in Canada to use a whole-family approach to examine the characteristics of a CYSHCN cohort and their mothers and siblings who received and did not receive publicly funded respite services. Evidence on the socioeconomic and health characteristics related to the receipt of respite is beneficial in developing responsive respite policy and programming. Our findings reveal disparities in receipt of respite for many Manitoba families of CYSHCN and demonstrate inequity in the receipt of respite services along income lines. This is important information that can be used to examine and enhance respite policy and practice to develop an equitable and responsive respite care program to address the unique needs of Manitoba CYSHCN and their families.

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Conflicts of interest

The authors have no conflicts of interest to declare.

Ethics statement

The Health Research Ethics Board at the University of Manitoba (H2019:106) and the Health Information Privacy Committee of the Government of Manitoba (File No.2019/20-01) approved this study. The need for informed consent was waived by the Health Research Ethics Board at the University of Manitoba because data was obtained from retrospective and de-identified databases. All methods were performed following the relevant guidelines and regulations.

Data availability statement

The data analyzed during the current study are available from the corresponding author Dr. Roberta Woodgate on reasonable request.

References

1. Buckley N, Glasson EJ, Chen W, Epstein A, Leonard H, Skoss R, et al. Prevalence estimates of mental health problems in children and adolescents with intellectual disability: A systematic review and meta-analysis. Aust N Z J Psychiatry. 2020;54(10):970-84. https://doi.org/10.1177/0004867420924101

2. Reddihough D, Leonard H, Jacoby P, Kim R, Epstein A, Murphy N, et al. Comorbidities and quality of life in children with intellectual disability. Child: Care, Health and Development. 2021;47(5):654-66. https://doi.org/10.1111/cch.12873

3. Canadian Institute for Health Information. Children and Youth with Medical Complexity in Canada Ottawa, ON2020. Available from: https://www.cihi.ca/sites/default/files/document/children-youth-with-medical-complexity-report-en.pdf

4. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttmann A. Patterns and costs of health care use of children with medical complexity. Pediatrics. 2012;130(6):e1463-70. https://doi.org/10.1542/peds.2012-0175

5. Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. Arch Pediatr Adolesc Med. 2011;165(11):1020-6. https://doi.org/10.1001/archpediatrics.2011.172

6. Sil S, Woodward KE, Johnson YL, Dampier C, Cohen LL. Parental Psychosocial Distress in Pediatric Sickle Cell Disease and Chronic Pain. J Pediatr Psychol. 2021;46(5):557-69. https://doi.org/10.1093/jpepsy/jsaa130

7. Marquis S, McGrail K, Hayes MV. Using administrative data to examine variables affecting the mental health of siblings of children who have a developmental disability. Res Dev Disabil. 2020;96:103516. https://doi.org/10.1016/j.ridd.2019.103516

8. Marquis SM, McGrail K, Hayes MV. A population-level study of the mental health of siblings of children who have a developmental disability. SSM Popul Health. 2019;8:1-11. https://doi.org/10.1016/j.ssmph.2019.100441

9. Keilty K, Cohen E, Ho M, Spalding K, Stremler R. Sleep disturbance in family caregivers of children who depend on medical technology: A systematic review. J Pediatr Rehabil Med. 2015;8(2):113-30. https://doi.org/10.3233/PRM-150325

10. Benson PR. The impact of child and family stressors on the self-rated health of mothers of children with autism spectrum disorder: Associations with depressed mood over a 12-year period. Autism. 2018;22(4):489-501. https://doi.org/10.1177/1362361317697656

11. Woodgate RL, Edwards M, Ripat JD, Borton B, Rempel G. Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. BMC Pediatr. 2015;15:197. https://doi.org/10.1186/s12887-015-0514-5

12. Woodgate RL, Edwards M, Ripat J. How families of children with complex care needs participate in everyday life. Soc Sci Med. 2012;75(10):1912-20. https://doi.org/10.1016/j.socscimed.2012.07.037

13. Woodgate RL, Zurba M, Edwards M, Ripat JD, Rempel G. The embodied spaces of children with complex care needs: Effects on the social realities and power negotiations of families. Health Place. 2017;46:6-12. https://doi.org/10.1016/j.healthplace.2017.04.001

14. Edelstein H, Schippke J, Sheffe S, Kingsnorth S. Children with medical complexity: a scoping review of interventions to support caregiver stress. Child Care Health Dev. 2017;43(3):323-33. https://doi.org/10.1111/cch.12430

15. Murphy M, Hill K, Begley T, Brenner M, Doyle C. Respite Care for Children with Complex Care Needs: A Literature Review. Compr Child Adolesc Nurs. 2021:1-10. https://doi.org/10.1080/24694193.2021.1885523

16. Canadian Healthcare Association. Respite Care in Canada Ottawa2012. Available from: https://www.healthcarecan.ca/wp-content/themes/camyno/assets/document/PolicyDocs/2012/External/EN/RespiteCare_EN.pdf

17. Damiani G, Rosenbaum P, Swinton M, Russell D. Frequency and determinants of formal respite service use among caregivers of children with cerebral palsy in Ontario. Child: Care, Health & Development. 2004;30(1):77-86. https://doi.org/10.1111/j.1365-2214.2004.00391.x

18. Robertson J, Hatton C, Wells E, Collins M, Langer S, Welch V, et al. The impacts of short break provision on families with a disabled child: an international literature review. Health Soc Care Community. 2011;19(4):337-71. https://doi.org/10.1111/j.1365-2524.2010.00977.x

19. Canchild Centre for Disability Research. Family Centred Service in Ontario: A "Best Practice" Approach for Children with Disabilities and Their Families 2002. Available from: https://canchild.ca/system/tenon/assets/attachments/000/000/632/original/FCSinbriefNov2002.pdf

20. Christi RA, Roy D, Heung R, Flake E. Impact of Respite Care Services Availability on Stress, Anxiety and Depression in Military Parents who have a Child on the Autism Spectrum. J Autism Dev Disord. 2022:1-15. https://doi.org/10.1007/s10803-022-05704-x

21. Sung M, Park J. The Effects of a Family Support Program Including Respite Care on Parenting Stress and Family quality of Life Perceived by Primary Caregivers of Children with Disabilities in Korea. International Journal of Special Education. 2012;27(3):188-98. https://eric.ed.gov/?id=EJ1001071

22. Doig JL, McLennan JD, Urichuk L. 'Jumping through hoops': parents' experiences with seeking respite care for children with special needs. Child Care Health Dev. 2009;35(2):234-42. https://doi.org/10.1111/j.1365-2214.2008.00922.x

23. Childhood Disability LINK. Respite Flow Chart MB 2019. Available from: https://www.childhooddisability.ca/wp-content/uploads/2019/02/Respite-Flow-Chart-MB.pdf

24. Manitoba Department of Families. Children's disABILITY Services (CDS) n.d. Available from: https://www.gov.mb.ca/fs/cds/index.html

25. Canadian Home Care Association. Home and Community-based Services for Children with Complex Care Needs Mississauga, ON2016. Available from: https://cdnhomecare.ca/wp-content/uploads/2020/02/CHCA-Children-with-Complex-Care-Needs.pdf

26. Almasri N, Palisano RJ, Dunst C, Chiarello LA, O'Neil ME, Polansky M. Profiles of family needs of children and youth with cerebral palsy. Child: Care, Health and Development. 2012;38(6):798-806. https://doi.org/10.1111/j.1365-2214.2011.01331.x

27. Kirk RS, Kagan J. A research agenda for respite care: Deliberations of an expert panel of researchers, advocates and funders: National Respite Network and Resource Center; 2015. Available from: http://lx.iriss.org.uk/sites/default/files/arch_respite

28. Khanlou N, Haque N, Sheehan S, Jones G. "It is an Issue of not Knowing Where to Go": Service Providers' Perspectives on Challenges in Accessing Social Support and Services by Immigrant Mothers of Children with Disabilities. J Immigr Minor Health. 2015;17(6):1840-7. https://doi.org/10.1007/s10903-014-0122-8

29. de Banate MA, Maypole J, Sadof M. Care coordination for children with medical complexity. Curr Opin Pediatr. 2019;31(4):575-82. https://doi.org/10.1097/MOP.0000000000000793

30. Anonymized for blind review. 2023.

31. Brownell MD, Jutte DP. Administrative data linkage as a tool for child maltreatment research. Child Abuse Negl. 2013;37(2-3):120-4. https://doi.org/10.1016/j.chiabu.2012.09.013

32. Wijlaars LPMM, Gilbert R, Hardelid P. Chronic conditions in children and young people: learning from administrative data. Arch Dis Child. 2016;101(10):881-5. https://doi.org/10.1136/archdischild-2016-310716

33. Gray C, Leonard H, Cooper MN, Rai D, Glasson EJ. The application of population data linkage to capture sibling health outcomes among children and young adults with neurodevelopmental conditions. A scoping review. Int J Popul Data Sci. 2025;10(1):2413. https://doi.org/10.23889/ijpds.v10i1.2413

34. Anonymized for blind review. 2024.

35. Manitoba Centre for Health Policy. The Manitoba Population Research Data Repository: University of Manitoba; n.d. Available from: https://umanitoba.ca/manitoba-centre-for-health-policy/data-repository

36. Hamm NC, Hamad AF, Wall-Wieler E, Roos LL, Plana-Ripoll O, Lix LM. Multigenerational health research using population-based linked databases: an international review. Int J Popul Data Sci. 2021;6(1):1686. https://doi.org/10.23889/ijpds.v6i1.1686

37. Jutte DP, Roos LL, Brownell MD. Administrative record linkage as a tool for public health research. Annu Rev Public Health. 2011;32:91-108. https://doi.org/10.1146/annurev-publhealth-031210-100700

38. Roos LL, Nicol P. A Research Registry: Uses, Development, and Accuracy. J Clin Epidemiol. 1999;52(1):39-47. https://doi.org/10.1016/s0895-4356(98)00126-7

39. Chartier M, Brownell M, MacWilliam L, Valdivia J, Nie Y, Ekuma O, et al. The Mental Health of Manitoba's Children Winnipeg, MB.2016. Available from: http://mchp-appserv.cpe.umanitoba.ca/reference/MHKids_web_report.pdf

40. Brownell M, Chartier M, Santos R, Ekuma O, Au W, Sarkar J, et al. How are Manitoba's Children Doing? Winnipeg, MB.2012. Available from: http://mchp-appserv.cpe.umanitoba.ca/reference/mb_kids_report_WEB.pdf

41. Chartier M, Bolton J, Mota N, MacWilliam L, Ekuma O, Nie Y, et al. Mental Illness among Adult Manitobans Winnipeg, MB2018. Available from: http://mchp-appserv.cpe.umanitoba.ca/reference/mh2015_Report_web.pdf

42. Fransoo R, Mahar A, Team. TNTK, Anderson A, Prior H, Koseva I, et al. The 2019 RHA Indicators Atlas Winnipeg, MB2019. Available from: http://mchp-appserv.cpe.umanitoba.ca/reference/RHA_Report_web.pdf

43. Deyo RA, Cherkin DC, Ciol MA. Adapting a Clinical Comorbidity Index for Use with ICD-9_CM Administrative Databases. Journal of Clinical Epidemiology. 1992;45(6):613-9. https://doi.org/10.1016/0895-4356(92)90133-8

44. Charlson ME, Pompei P, Ales KL, MacKenzie R. A New Method of Classifying Prognostic Comorbidity in Longitudinal Studies: Development and Validation. J Chron Dis. 1987;40(5):373-83. https://doi.org/10.1016/0021-9681(87)90171-8

45. Halfon P, Eggli Y, van Melle G, Chevalier J, Wasserfallen J-B, Burnand B. Measuring potentially avoidable hospital readmissions. Journal of Clinical Epidemiology. 2002;55:573-87. https://doi.org/10.1016/s0895-4356(01)00521-2

46. Schneeweiss S, Wang PS, Avorn J, Glynn RJ. Improved Comorbidity Adjustment for Predicting Mortality in Medicare Populations. Health Services Research. 2003;38(4):1103-20. https://doi.org/10.1111/1475-6773.00165

47. Charlson ME, Szatrowski TP, Peterson J, Gold J. Validation of a Combined Comorbidity Index. Journal of Clinical Epidemiology. 1994;47(11):1245-51. https://doi.org/10.1016/0895-4356(94)90129-5

48. Charlson ME, Carrozzino D, Guidi J, Patierno C. Charlson Comorbidity Index: A Critical Review of Clinimetric Properties. Psychother Psychosom. 2022;91(1):8-35. https://doi.org/10.1159/000521288

49. Manitoba Centre for Health Policy. Concept: Charlson Comorbidity Index Winnipeg, Canada2021. Available from: http://mchp-appserv.cpe.umanitoba.ca/viewConcept.php?conceptID=1098

50. Horrill TC, Dahl L, Sanderson E, Munro G, Garson C, Fransoo R, et al. Cancer incidence, stage at diagnosis and outcomes among Manitoba First Nations people living on and off reserve: a retrospective population-based analysis. CMAJ Open. 2019;7(4):E754-E60. https://doi.org/10.9778/cmajo.20190176

51. Brusselaers N, Lagergren J. The Charlson Comorbidity Index in Registry-based Research. Methods Inf Med. 2017;56(5):401-6. https://doi.org/10.3414/ME17-01-0051

52. Hessels AJ, Liu J, Cohen B, Shang J, Larson EL. Severity of Illness Measures for Pediatric Inpatients. J Healthc Qual. 2018;40(5):e77-e89. https://doi.org/10.1097/JHQ.0000000000000135

53. Torres-Espindola LM, Demetrio-Rios J, Carmona-Aparicio L, Galvan-Diaz C, Perez-Garcia M, Chavez-Pacheco JL, et al. Comorbidity Index as a Predictor of Mortality in Pediatric Patients With Solid Tumors. Front Pediatr. 2019;7:48. https://doi.org/10.3389/fped.2019.00048

54. Ergenc Z, Kepenekli E, Cetin E, Ersoy A, Korkmaz B, Selcik R, et al. Incidence of multisystem inflammatory syndrome in children and the comorbidity scores in pediatric coronavirus disease 2019 cases. Pediatr Int. 2022;64(1):e15084. https://doi.org/10.1111/ped.15084

55. Sun JW, Bourgeois FT, Haneuse S, Hernandez-Diaz S, Landon JE, Bateman BT, et al. Development and Validation of a Pediatric Comorbidity Index. Am J Epidemiol. 2021;190(5):918-27. https://doi.org/10.1093/aje/kwaa244

56. Woodgate RL, Edwards M, Ripat JD, Rempel G, Johnson SF. Siblings of children with complex care needs: their perspectives and experiences of participating in everyday life. Child: Care, Health and Development. 2016;42(4):504-12. https://doi.org/10.1111/cch.12345

57. Manitoba Advocate for Children and Youth. Bridging the gaps: achieving substantive equality for children with disabilities in Manitoba Winnipeg, MB2021. Available from: https://manitobaadvocate.ca/wp-content/uploads/MACY-Report-Bridging-the-Gaps-Achieving-Substantive-Equality-for-Children-with-Disabilities-in-Manitoba.pdf

58. McLennan JD, Bahadur A, Cobigo V, Hrycko S, Fulford C. Cross-sector service use patterns among children with developmental disabilities in a district in Canada. J Appl Res Intellect Disabil. 2021;34(2):546-55. https://doi.org/10.1111/jar.12821

59. Simpson F. Access to Respite Care for Parents Who Have Children With Disabilities in B.C.: Simon Fraser University; 2009. Available from: https://summit.sfu.ca/_flysystem/fedora/sfu_migrate/9415/etd4410_FSimpson.pdf

60. Dunbrack J. Respite for Family Caregivers. An Environmental Scan of Publicly-funded Programs in Canada: Health Canada; 2003. Available from: https://www.canada.ca/content/dam/hc-sc/migration/hc-sc/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2003-respite-releve/2003-respite-releve-eng.pdf

61. Masefield SC, Prady SL, Sheldon TA, Small N, Jarvis S, Pickett KE. The Effects of Caring for Young Children with Developmental Disabilities on Mothers' Health and Healthcare Use: Analysis of Primary Care Data in the Born in Bradford Cohort. Journal of Developmental and Physical Disabilities. 2021;34(1):67-87. https://doi.org/10.1007/s10882-021-09789-7

62. Nageswaran S. Respite Care for Children With Special Health Care Needs. Arch Pediatr Adolesc Med. 2009;163(1):49-54. https://doi.org/10.1001/archpediatrics.2008.504

63. Maternal and Child Health Bureau. Children with special health care needs 2019. Available from: https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn

64. Dyches TT, Christensen R, Harper JM, Mandleco B, Roper SO. Respite Care for Single Mothers of Children with Autism Spectrum Disorders. J Autism Dev Disord. 2016;46(3):812-24. https://doi.org/10.1007/s10803-015-2618-z

65. Cooke E, Smith V, Brenner M. Parents' experiences of accessing respite care for children with Autism Spectrum Disorder (ASD) at the acute and primary care interface: a systematic review. BMC Pediatr. 2020;20(1):244. https://doi.org/10.1186/s12887-020-02045-5

66. Brehaut JC, Guevremont A, Arim RG, Garner RE, Miller AR, McGrail KM, et al. Using Canadian administrative health data to examine the health of caregivers of children with and without health problems: A demonstration of feasibility. Int J Popul Data Sci. 2019;4(1):584. https://doi.org/10.23889/ijpds.v4i1.584

67. Biel MG, Tang MH, Zuckerman B. Pediatric mental health care must be family mental health care. JAMA Pediatr. 2020;174:519-20. https://doi.org/10.1001/jamapediatrics.2020.0065

68. Davey H, Imms C, Fossey E. "Our child's significant disability shapes our lives": experiences of family social participation. Disabil Rehabil. 2015;37(24):2264-71. https://doi.org/10.3109/09638288.2015.1019013

69. Carbone S, Fraser A, Ramburuth R, Nelms L. Breaking cycles, building futures: Promoting inclusion of vulnerable families in antenatal and universal early childhood services Melbourne, Australia 2003. Available from: https://library.bsl.org.au/jspui/bitstream/1/1515/1/bcbf%20lit%20review%20april%20final.pdf

70. Mendoza J, Katz LG, Robertson AS, Rothenberg D. Connecting with parents in the early years. Champaign, IL: University of Illionois at Urb; 2003.

71. Graaf G, Baiden P, Boyd G, Keyes L. Barriers to Respite Care for Children with Special Health Care Needs. J Dev Behav Pediatr. 2022;43(3):117-29. https://doi.org/10.1097/DBP.0000000000000992

72. Raouafi S, Achiche S, Raison M. Socioeconomic disparities and difficulties to access to healthcare services among Canadian children with neurodevelopmental disorders and disabilities. Epidemiol Health. 2018;40:e2018010. https://doi.org/10.4178/epih.e2018010

73. Brownell M, Martens PJ, Kozyrskyj A, Fergusson P, Lerfald J, Mayer t, et al. Assessing the Health of Children in Manitoba: A Population-Based Study Winnipeg: Manitoba Centre for Health Policy and Evaluation Winnipeg, MB: Manitoba Centre for Health Policy and Evaluation; 2001. Available from: http://mchp-appserv.cpe.umanitoba.ca/reference/child_pdf_one_document.pdf

74. Kelly C, Craig S, McConkey R. Supporting family carers of children and adults with intellectual

disability. Journal of Social Work. 2020;20(5):639-56. https://doi.org/10.1177/1468017319860312

75. Russell MJ, Zhang Y, Cui X, Tough S, Zwicker JD. Use of family disability service by families with young children with disabilities. Dev Med Child Neurol. 2021;63(1):81-8. https://doi.org/10.1111/dmcn.14478

76. Kelly C, Dansereau L, Balkaran K, Tingey E, Hande MJ, Aubrecht K, et al. Directly-Funded Care Programs in Canada. Winnipeg, Manitoba: Centre on Aging; 2020. Available from: https://mspace.lib.umanitoba.ca/server/api/core/bitstreams/c952b591-3ed5-4194-8ef8-b517d72d5b55/content

77. Children's disABILITY Services. Guide to Self-Managed Services Winnipeg, MBn.d. Available from: https://www.gov.mb.ca/fs/cds/pubs/cds-guide-to-self-managed-services.pdf

78. Kelly C, Jamal A, Aubrecht K, Grenier A. Emergent Issues in Directly-Funded Care: Canadian Perspectives. J Aging Soc Policy. 2021;33(6):626-46. https://doi.org/10.1080/08959420.2020.1745736

79. Goudie A, Havercamp S, Jamieson B, Sahr T. Assessing functional impairment in siblings living with children with disability. Pediatrics. 2013;132(2):e476-83. https://doi.org/10.1542/peds.2013-0644

80. Cohen E, Patel D. Responding to the rising number of children living with complex chronic conditions. CMAJ. 2014;186(16):1199-200. https://doi.org/10.1503/cmaj.141036

81. Flegel K. Chronically ill children and fragile families. CMAJ 2014;186(16):1195. https://doi.org/10.1503/cmaj.141207

82. Canadian Institute for Health Information. Trends in Income-Related Health Inequalities in Canada Ottawa, ON: CIHI; 2015. Available from: https://www.cihi.ca/en/trends-in-income-related-health-inequalities-in-canada

83. Dias BC, Marcon SS, Reis PD, Lino IGT, Okido ACC, Ichisato SMT, et al. Family dynamics and social network of families of children with special needs for complex/continuous cares. Rev Gaucha Enferm. 2020;41:e20190178. https://doi.org/10.1590/1983-1447.2020.20190178

84. Boling W. The Health of Chronically Ill Children. Lessons Learned from Assessing Family Caregive Quality of Life. Fam Community Health. 2005;28(2):176-83. https://doi.org/10.1097/00003727-200504000-00009

85. Barr J, McLeod S. They never see how hard it is to be me: siblings' observations of strangers, peers and family. Int J Speech Lang Pathol. 2010;12(2):162-71. https://doi.org/10.3109/17549500903434133

86. Van Dongen T, Sabbe B, Glazemakers I. Collaboration for children with complex needs: What adolescents, parents, and practitioners tell us. J Child Health Care. 2020;24(1):19-32. https://doi.org/10.1177/1367493518823906

87. Glasson EJ, Hussain R. Linked data: opportunities and challenges in disability research. J Intellect Dev Disabil. 2008;33(4):285-91. https://doi.org/10.1080/13668250802441409

88. Manitoba Centre for Health Policy. Concept: Income Quintiles - Child Health Income Quintiles n.d. Available from: http://mchp-appserv.cpe.umanitoba.ca/viewConcept.php?conceptID=1161

Abbreviations

CYSHCN:	Children and youth with special health care needs (Children and youth with special health care needs
CDS:	Children's disABILITY Services (provincially funded program that supports families who are raising a child (or children) with developmental and physical disabilities in Manitoba)
CLDS:	Community Living disABILITY Services (provincially funded program that supports eligible adults with intellectual disabilities in Manitoba)
MCHP:	Manitoba Centre for Health Policy
PHIN:	Personal Health Information Number
ICD:	International Classi?cation of Diseases
ICD-9-CM:	International Classification of Diseases, 9th Revision, Clinical Modification
MR:	Mild Mental Retardation
ASD:	Autism Spectrum Disorder
ICD-10-CA:	International Classification of Diseases, 10th Revision, Canada
MH:	Multiple Handicaps
HOH/VI:	Hard of Hearing/Vision Impairment
EBD:	Emotional Behavioural Disorder
IQ:	Income Quintile
Q1-Q5:	Income Quintile 1; Income Quintile 5
CCI:	Charlson Comorbidity Index
BIC:	Bayesian Information Criterion
SAS:	Statistical Analysis Software
$CAD:	Canadian dollar