Disability and Health Journal 14 (2021) 101118

Contents lists available at ScienceDirect

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

Original Article

Cross-ministry data on service use and limitations faced by children in special education

Matthew Joseph Russell, PhD [a, b, c, *], Craig William Michael Scott, MPP [a],
Kara Murias, MD, PhD [d], W. Ben Gibbard, MD [d], Xinjie Cui, PhD [c],
Suzanne Tough, PhD [b, d, 1], Jennifer D. Zwicker, PhD [a, e, 1]

[a] *School of Public Policy, University of Calgary, 906 8th Avenue S.W., 5th Floor, Calgary, Alberta, T2P 1H9, Canada*
[b] *Community Health Sciences, Cumming School of Medicine, University of Calgary, 3280 Hospital Drive NW, Calgary, Alberta, T2N 4Z6, Canada*
[c] *PolicyWise for Children & Families, 1000-9925 109 St NW, Edmonton, AB T5K 2J8, Canada*
[d] *Pediatrics, Cumming School of Medicine, University of Calgary, 28 Oki Drive NW, Calgary, Alberta, T3B 6A8, Canada*
[e] *Faculty of Kinesiology, University of Calgary, 376 Collegiate Blvd NW, Calgary, Alberta, T2N 1N4, Canada*

ARTICLE INFO

Article history:
Received 30 July 2020
Received in revised form
8 May 2021
Accepted 10 May 2021

Keywords:
Child
Disability
Special education
Functional limitation
Big data

ABSTRACT

Background: Children with disabilities often face limitations that cross support sectors. **Objective**: Our aim was to measure cross-ministry service use, outcomes, and functional limitations faced by children who qualified for special education.
Methods: We used longitudinal British Columbia ministry data linked to children (0-18y) registered in K-12 education. Children were grouped by special education funding (most to least; Level 1, Level 2, Level 3, Unfunded, and no special education), and related to 1) service use patterns, 2) the age they first used disability services, and 3) functional limitations reported in health visits. We also reported how length of special education use related to disability service use.
Results: Of 111,274 children, 154(0.1%) were Level 1, 4427(4.0%) Level 2, 2897(2.6%) Level 3, 13472(12.1%) Unfunded, and 90324(81.2%) not in special education. Children with higher funding levels, compared to lower levels of funding, generally were more likely to experience poorer outcomes, have functional limitations, have service needs, and receive early support. One exception was children with serious behavioral/mental health special education coding, which had poorer outcomes for their level of funding. Children received child disability supports early (about half of users started by 4y), but use was mostly limited to those with many years (9+years) of funded special education (70.7% of the all users) and biased to certain special education codes (i.e., Level 1, severe intellectual disability, and autism).
Conclusions: This study provides evidence of the long-term, diverse needs of children in special education and may be used to inform decisions surrounding their support.

Introduction

Children with disabilities have heterogeneous conditions that affect their lives, and are a vulnerable population that experiences significant health disparities.[1–7] While an exact prevalence of childhood disability is difficult to ascertain with current data, an estimated 12–13% of children and youth in Canada have a disability.[8,9] Furthermore, an estimated 5–9% of Canadian children[10–12] have neurodevelopmental disorders (NDD), which are chronic neurological conditions that often present substantial[7–9] functional and/or behavioral challenges.[13–16] Children with disabilities often face mental health challenges, either as concurrent conditions or as their primary source of disability.[6,16] Health, education and social supports are often provided to address functional and activity limitations experienced by children with disabilities to facilitate their full inclusion and participation in society; however, children with disabilities have low rates of educational achievement and higher rates of service use related to their complex needs, compared to other children.[5,6,17] Despite the existence of education and social support services for children with disabilities, barriers to

---

[*] Corresponding author. School of Public Policy, 906 8th Avenue S.W., 5th floor, Calgary, Alberta, T2P 1H9, Canada.
E-mail address: matthew.russell@ucalgary.ca (M.J. Russell).
[1] Shared senior authors.

https://doi.org/10.1016/j.dhjo.2021.101118

service use are often reported by families.[18–20] Eligibility for support services is often dependent on a child's diagnosis, which may miss specific functional needs that interfere with their engagement in society.[21–23]

Special education programs are designed to provide individualized education plans that target the functional needs of children with disabilities.[24,25] Unfortunately, due to a lack of available long-term longitudinal data, little is known about the actual use of special education and other supports services across childhood, despite known disparities in outcomes for children with disabilities. However, based on current available data, we have evidence that children in special education are more likely to have costly healthcare needs (e.g., in the top 5% based on healthcare costs), mental health needs, high school incompletion, and use of child disability services, compared to children not in special education.[5,6,15,26] Beyond this impact, families often report inequities such as higher financial costs, reduced work hours,[27–30] and higher rates of poverty compared to caregivers who do not have a children with disabilities.[17] Furthermore, early evidence supports that special education coding relates to different outcomes in Canada.[5,6] For example, Albertan children with more severe special education codes were more likely to use child disability supports in the early years, than children with less severe coding.[6] Other research found that Albertan youth with certain types of disability (e.g., severe special education codes and severe intellectual disorder) we more likely to have poor educational achievement than those with other special education coding.[5] As a limitation, these studies were limited to short-term longitudinal outcomes.

Research objectives

This study uses longitudinal cross-ministerial administrative data from British Columbia (BC), Canada to measure long-term service use patterns associated with the complex needs of children with different types of disabilities. Findings inform on disparities in access to services across the heterogeneous population of children, and on their diverse needs. This knowledge is critical to facilitate the inclusion and participation of children with disabilities.[31]

Method

Dataset

We used administrative data from 3 BC governmental ministries (Education, Health, and Children & Family Development). Population Data BC (a multi-university group)[32] performed probabilistic data linkage and anonymization as part of the BC Government Data Innovation Program,[33] with analyses done in a secure environment that allowed access to anonymized data only in the environment, and required aggregation and vetting to access results outside. As the BC ministries partnered on this project to provide information on children with disabilities, analyses reflect stakeholder engagement and feedback to maximize relevance to actual program use.

Study population

British Columbia had a total population of 4.65 million people in 2016. The study population consisted of BC children who met 3 criteria: 1) were born in the 1995/96 to 1998/99 fiscal year (April 1st to March 31st) and were 18 years old in 2013/14 to 2016/17; 2) were registered in the BC healthcare registry or education system every year until age 18; and 3) did not appear in a BC independent school registration. This resulted in a sample of 111,274 children, 35,556 children were excluded due to the continuous registration requirement and 30,609 children due to the independent school requirement. Continuous registration ensured that children resided in BC across the study and no independent school registration ensured special education code availability.

Special education coding

Children were defined by their *special education* funding *level*, the level of funding that children had for a majority of their school years (besides years without coding). In 2016/17 BC schools were allocated different levels of funding for children in special education; CAD $37,700 a year for Level 1 codes (physically dependent, deafblind), CAD $18,850 for Level 2 codes (severe [moderate to profound] intellectual disability, autism, physical disability or chronic health, visual impairment, hearing impairment), CAD $9500 for Level 3 codes (serious behavioral/mental health issues), and no additional funding for Unfunded code (mild intellectual, moderate behavioral or mental health, learning disabilities). All four levels were supported by other base education funding. In the case of an equal period of support, the higher funding level was used for coding. Fig. 2 splits by funded (level 1–3) and unfunded codes. For the supplementary analyses, we split children by *special education code* that children had for a majority of their school years (e.g., visual impairment or autism). The codes and their levels are described in supplementary SM-1. Children with special education coding were compared to children that had *no special education* code.

Special education for this study is based on students publicly funded by BC, with opportunities provided to students in the classroom, as well as hospital education and homebound education services for those temporarily ill or hospitalized.[24]

Neurodevelopmental disorder and mental health functional limitations

We investigated how NDD and mental health functional limitations related to special education coding, as they have been previously connected to those with disabilities.[6–16] We modified a previously developed ICD code NDD definition that used healthcare data to characterize limitations of children with NDD the domains of motor, speech, learning, social, sensory, and neuropsychological functioning.[12] As the previous coding scheme was not meant to be exhaustive,[12,22] we used a consensus building strategy between two physicians specializing in NDD to inform ICD code additions or deletions, with the support of an ICD-9 to ICD-10 (and back) translator.[34] In addition, we included a domain related to mental health functioning, based on previous findings.[22,35] The full list of codes is provided and described in supplementary SM-2.

NDD diagnoses were defined by healthcare coding in at least 2 physician visits or 1 hospitalization over time periods, in at least one of the domains.[12] Mental health diagnoses were defined by the presence of 1 physician visit or hospitalization after 10 years of age.[35] For our functional limitation analysis, the presence of 1 physician visit or hospitalization with a classification code for each domain was required as the goal was to provide evidence of functional concern.

Covariates

We investigated how special education use (age of first special education and years of special education), child characteristics (sex, diploma received, and ESL student), functional limitations (NDD diagnosis and mental health diagnosis), and service use (child disability service use, child-in-care, and top 5% hospitalized) related to special education coding. Covariates were chosen based on previous research on children in special education and are described in detail in supplementary SM-3.[5,6,15,26] Individuals without service use data were coded as not using services. As physician visits and hospital services in BC are publicly funded, health variables used should cover most of the health-related visits/diagnoses in the healthcare system.

Special Education use.

1. *Age of first special education* is the age (years) of the child's first instance of their most frequent special education code.
2. *Years of special education* is the total years with their most frequent special education code.

Child Characteristics.

3. *Sex* is the value reported in the healthcare registry (male/female).
4. *Diploma received* is an award of an accredited high-school diploma by age 18 (yes/no).
5. *ESL student* is ever being supported for English as a Second Language (yes/no).

Functional limitations.

6. *NDD diagnosis* is ever having a neurodevelopmental disorder diagnosis (yes/no).
7. *Mental Health diagnosis* is ever having a mental health diagnosis (yes/no).

Service Use.

8. *Child disability service use* is ever using provincial child disability services (yes/no).
9. *Child-in-care* is ever being placed outside into foster care/under temporary or permanent guardianship for safety reasons by provincial programs, excluding out-of-home care for disability (yes/no).
10. *Top 5% hospitalized* is ever being hospitalized in the healthcare system 5 or more times. Five or more is the top 5% of hospital usage, based on the entire cohort (yes/no). This outcome was chosen as NDDs have been linked to chronic health conditions and increased hospitalization.[12,36,37]

Data analysis

SAS Enterprise Guide 7.1 was used for all analyses. Descriptive statistics were used to compare special education use, child characteristics, functional limitations, and service use for each level of special education funding to those with no special education. Count variables are reported as frequencies and proportions, and variables with years are reported as medians and interquartile ranges (Table 1). This analysis was split by each special education code in supplementary Table S-1.

Second, descriptive analyses were used to report the cumulative percent of children aged 0-18y that had received the following: a) their first special education code, by level; and b) their first NDD diagnosis and first used child disability services (Fig. 1; e.g., a 50% for NDD diagnosis represents that half of children that received a NDD diagnosis had done so at this age).

Third, descriptive analyses were used to report how total years of special education (1-4y; 5-8y; 9 + y) related to a) NDD diagnosis and b) child disability service use, by funded status (Funded: Level 1–3 vs. Unfunded). Fig. 2 shows the proportion of the group, with counts reported in supplementary Table S-2.

Finally, we calculated the percentage of children with each funding level that had a healthcare visit for each functional limitation domain. Table 2 highlights funding levels with at least 33% of children experiencing functional limitation, while supplementary Table S-3 reports the percentages/counts. In addition, we report results for each special education code in supplementary Table S-4 & S-5.

Results

Child characteristics

Of 111,274 children, 154(0.1%) had a Level 1 code, 4427(4.0%) had a Level 2 code, 2897(2.6%) had a Level 3 code, 13,472(12.1%) had an Unfunded code, and 90,324(81.2%) were not in special education between the ages of 0-18y (Table 1). While children with Level 1 codes, Level 3 codes, and those with no special education were ~50% male, Level 2 (68.7%) and Unfunded (67.3%) children were more likely to be male. About 20% of children in each group were in an English as a second language program, with a lower proportion for Level 1 children (10%). Children with higher funding levels were least likely to receive a diploma compared to those with less funding (e.g., Level 1: 9%; no special education: 86.6%). The proportion of children with Level 3 and Level 2 coding who received a diploma was 32.9% and 43.3%, respectively.

Service use

Generally, children coded with higher special education funding levels were more likely to use child disability services (Level 1: 79%; No special education: 0.06%) and were more often in the top 5% in hospitalizations (Level 1: 92%; No special education: 4.7%). Finally, children requiring services across all levels of special education support were more likely to be children-in-care than those not requiring special education, with the greatest proportion seen in Level 3 children (26.5% vs. 2.3% no special education).

Disability service use and functional limitations over time

There was a large range when children first received special education support and for how long they received this support. Children requiring higher funding generally received special education services at a younger age and were supported for a longer period of time. Children with Level 1 special education tended to be supported at the youngest ages followed by (in order) Level 2, Unfunded, and Level 3 (Fig. 1). Children with Level 3 coding (serious behavioral/mental health issues) had the latest special education start (median 15y) and the least years of support (median 2y).

Much of child disability service use was initiated early, by the age 4 (~50% of total use), with a smaller but steady increase from 4 to 18y. The highest proportion of child disability service use was observed by children Funded by special education supports long-term (9+years of support: 50.9%), with little service use seen for Unfunded children (9+years: 7.1%). Children with 9+ years of Funded support comprised 70.7% (1666 of 2358 children) of child disability service users (supplementary Table S-2).

For NDD diagnosis, an increase in first diagnosis was seen around 5-10y (roughly corresponding to entry into elementary/kindergarten), with a smaller but steady increase from 10 to 18y. Level 2 codes had a high rate of NDD diagnosis (78.4%), with Level 3 and Unfunded codes having much less (~40%). Also, quite a few children not supported by special education received NDD diagnosis (15.6%). Children requiring special education showed a higher proportion of mental health diagnosis than those not requiring special education. Notably, the greatest proportion of mental health

Table 1
Special education use, child characteristics, functional limitations, and service use by special education funding level. The top row reflects the total number (N) and percent of children with the level from the cohort, and the Ns and percent of children below are of each special education level.

Child characteristics, outcomes, and service use	No special education	Special education funding level			
		Unfunded	*Level 3*	*Level 2*	Level 1
Percent of cohort	81.2% (90324)	12.1% (13472)	2.6% (2897)	4.0% (4427)	0.1% (154)
	80.9–81.4	11.9–12.3	2.5–2.7	3.9–4.1	0.1–0.2
Age of first special education, median (IQR)	x	10 (4)	15 (4)	7 (5)	5 (1)
Years of special education coding, median (IQR)	x	6 (5)	2 (3)	9 (8)	13 (4)
Sex, Male	48.5% (43787)	67.3% (9060)	49.5% (1434)	68.7% (3039)	51.3% (79)
	48.2–48.8	66.5–68	47.7–51.3	67.3–70	43.4–59.2
Diploma received, Yes	86.6% (78227)	60.6% (8162)	32.9% (953)	43.3% (1918)	9.1% (14)
	86.4–86.8	59.8–61.4	31.2–34.6	41.9–44.8	4.6–13.6
ESL student, Yes	21.2% (19159)	21.7% (2929)	20.1% (582)	21.4% (949)	9.7% (15)
	20.9–21.5	21–22.4	18.6–21.5	20.2–22.6	5.1–14.4
NDD diagnosis, Yes	15.6% (14065)	40.9% (5512)	39.5% (1145)	78.4% (3471)	suppressed
	15.3–15.8	40.1–41.7	37.7–41.3	77.2–79.6	
Mental health diagnosis, Yes	19.3% (17401)	38.4% (5178)	72.5% (2101)	47.3% (2094)	24.7% (38)
	19–19.5	37.6–39.3	70.9–74.1	45.8–48.8	17.9–31.5
Child disability service use, Yes	.06% (57)	2.6% (352)	0.8% (22)	40.8% (1805)	79.2% (122)
	0–0.1	2.3–2.9	0.4–1.1	39.3–42.2	72.8–85.6
Child-in-care, Yes	2.3% (2050)	8.9% (1205)	26.5% (767)	16.5% (730)	16.2% (25)
	2.2–2.4	8.5–9.4	24.9–28.1	15.4–17.6	10.4–22.1
Top 5% hospitalized, Yes	4.7% (4290)	8.9% (1200)	16.0% (464)	32.8% (1452)	91.6% (141)
	4.6–4.9	8.4–9.4	14.7–17.4	31.4–34.2	87.2–95.9

aData are % (N) 95% confidence interval, unless otherwise stated.

diagnosis was seen for Level 3 children (72.5% vs. 19.3% no special education).

Children with higher funding levels and more years of special education support were more likely to have a NDD diagnosis (Funded [Level 1–3] for 1–4years: 37.8% of this group had a NDD, 9+years: 85.8%; Unfunded 1–4years: 33.9%, 9+years: 51.9%; Fig. 2).

Specific functional limitations

We split special education funding levels by functional limitation domains to provide additional information on limitations children with NDD experience (Table 2). We found that the higher the funding level, the more limitations children experienced. The most common limitations were learning (all special education users) and mental health issues (all special education users, except Level 1). In contrast, only Level 1 children experienced motor limitations above 33%, and speech and social limitations did not reach 33% in any levels. Social limitations were only above 33% for autism (76.2%; supplementary Table S-4).

Discussion

This study used longitudinal BC cross-ministry data on children, 0–18 years old, to measure child characteristics, cross-ministry service use, and functional limitations faced by children who qualified for special education. We found that 18.8% of BC children had at least 1 year of special education from age 0–18 years old. This is an increase from previous estimates of disability prevalence (12–13%) using cross-sectional or short-term data in Canada.[8,9] We identified that children's special education funding level was related to differences in NDD diagnosis, mental health diagnosis, child disability service use, child-in-care status, high school graduation, and hospitalization. Children's special education funding level was also associated with children's age of first use of child disability services and special education, whether they had a NDD diagnosis or used child disability services, and how many functional limitations they had.

Generally, children with level 1 and 2 funding allocations were identified at younger ages. This was most evident for the children in our cohort who were physically dependent or deafblind (Level 1). They received the highest special education funding allocation at the youngest ages and maintained this support. They also had the highest proportions of hospitalization and disability service use, and the lowest proportions of educational achievement. This supports other work indicating education support for this population places a higher priority on social and functional skills, relative to academic outcomes.[38] On the other hand, unfunded children had lower graduation rates and higher rates of mental health issues than those not in special education, but had little disability service use and less years of special education support. These support access patterns are sometimes described as ‘doing worse (as) doing better’, that more severe disabilities have more access to supports.[39]

An exception to higher funding levels allocated to children getting more support was children with serious behavioral/mental health issues. Our findings indicate that children with behavioral/mental health issues (Level 3) were older when they received special education funding and received this support for the shortest period of time, and had low rates of disability service use. This is despite ~40% of this group having a NDD diagnosis and ~75% having a mental health diagnosis. This is in line with findings suggesting mental health diagnosis and treatment often arises in adolescence,[40] but is an area of concern due to the poor outcomes for this group (i.e., high rates of high-school incompletion, child intervention, homelessness, and corrections involvement).[5,6]

Overall, poor outcomes (e.g., high school diploma and increased functional limitations) were seen among all children in special education, highlighting the need for early access to support when interventions are thought to be most effective.[41,42] This study found that provincial child disability service use was limited to those with funded special education codes with many years of special education (~70% of users) and to certain special education codes (i.e., the highest proportions of use were for Level 1, severe intellectual disorders, and autism). The degree of need for support partly explains this increased child disability service use. Early identification and eligibility are also of concern, due to their connection with support service access. While NDD diagnosis increased at the age of 5 (Fig. 1b), which corresponds with entrance into school (where diagnosis is often required for special education support), earlier screening and identification procedures might hasten disability

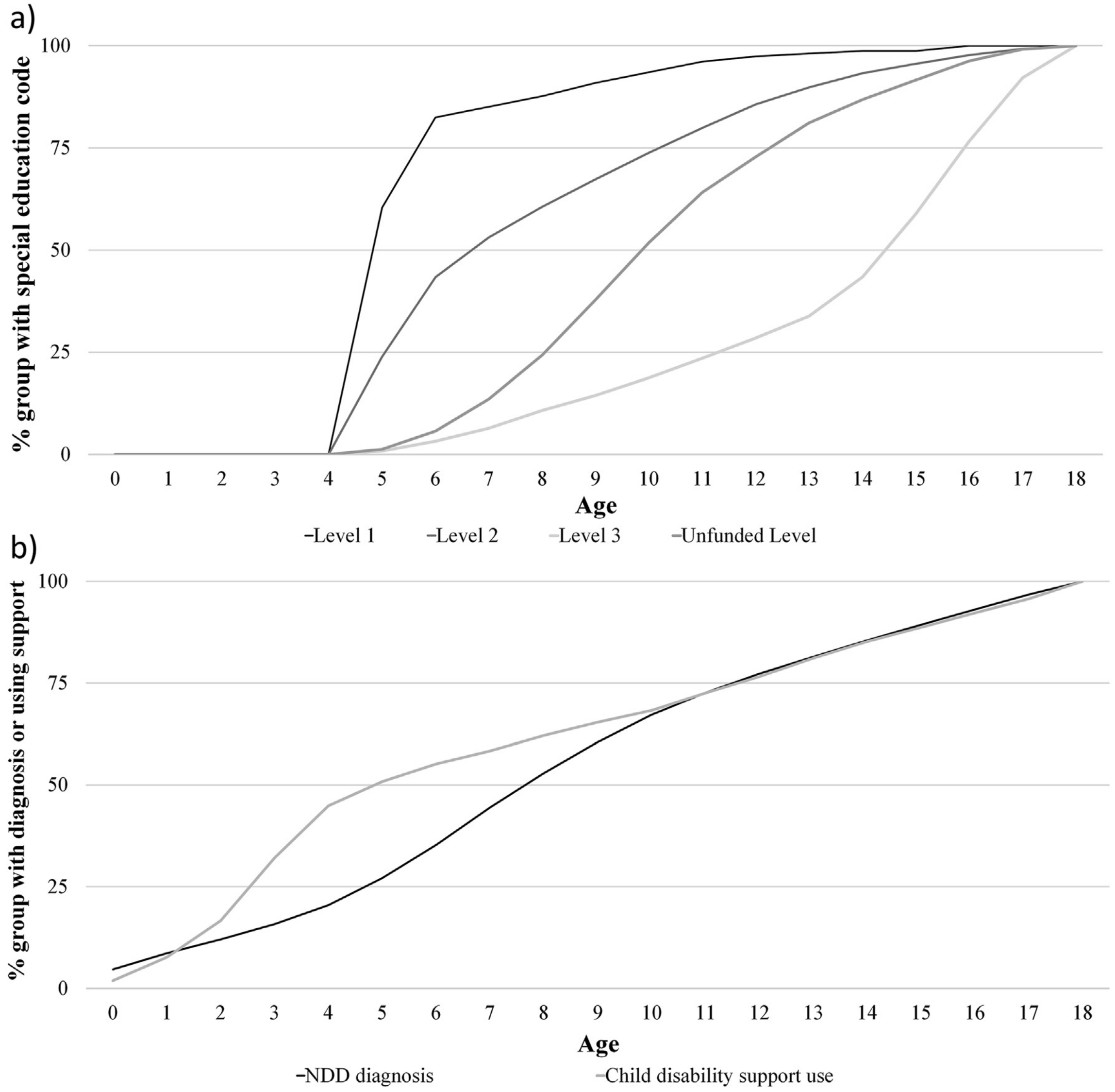

Fig. 1. The cumulative percent of children that had received: a) their first special education code, among each level of funding, and b) their first neurodevelopmental disorder (NDD) diagnosis and first use of child disability services. The cumulative percentage is of the total children that had ever received each.

support for those in need and improve outcomes.[6,43]

Finally, we found evidence that children in special education faced a wide range of functional limitations (e.g., motor, learning, and mental health), and children with higher special education funding levels generally had more limitations. *The diverse needs and multiple functional limitations faced by children in special education are key considerations as we seek to better* support *this population.*

Functional approaches to supporting children with disabilities

Children with disabilities are often classified in different ways: functional impairments (such as the functional limitations we investigated), etiology (the underlying disease; e.g., chromosomal abnormality) or using phenomenological approaches to classification (labelling a disorder based on constellations of symptoms, such as attention deficit hyperactivity disorder). Variations of these classifications span a wide range of limitations experienced by children, which further vary in severity and change over time.[44] These limitations may or may not be assigned a specific diagnosis or special education code. Furthermore, research suggests that the degree of functional limitation is more critical to determining unfavorable child outcomes compared to specific diagnoses.[23] As such, the provision of appropriate supports or interventions for a child requires assessment of the severity of the functional limitations they face in their lives, underlying impairments and medical conditions, and how these needs interact with their social, emotional, and environmental context.[22,23] *In order to better* support *children with disabilities and increase participation in society we need to avoid approaches based exclusively on diagnosis, and consider the complex, contextualized range of* support *needs for each child. We also need to effectively communicate limitations and complex needs faced by children across the communities that the child interacts with, as the impact is not isolated to one system.*

Limitations

This study had several limitations. First, administrative data suffers from data entry errors and difficulties in interpretation. For example, use of services may relate to need or access. Future research is needed to understand what services are difficult to

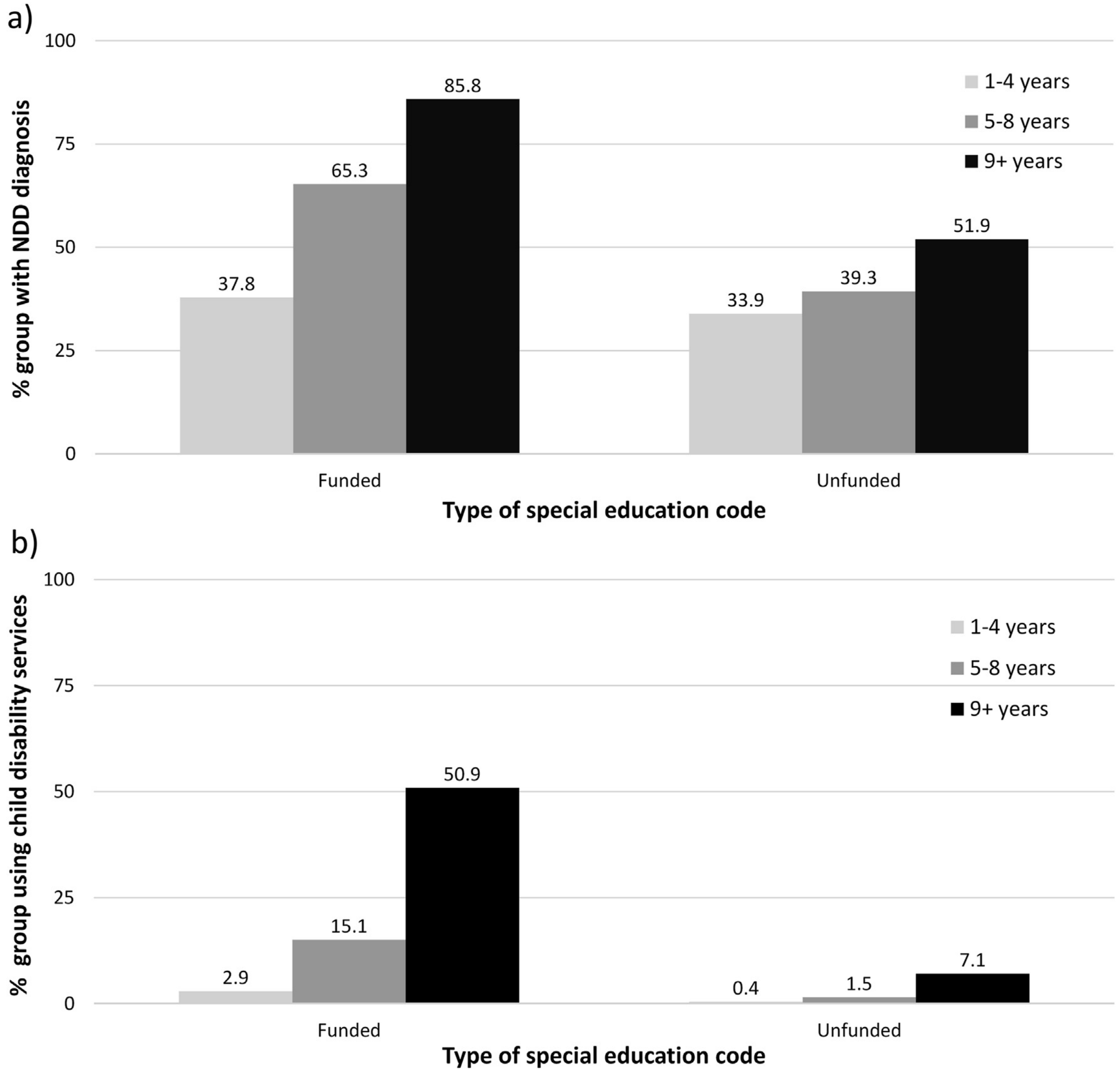

Fig. 2. Among children with 1–4, 5–8 and 9+ years of special education, the percentage of the group that had: a) a neurodevelopmental disorder (NDD) diagnosis and b) child disability service use, by funded (Level 1–3) and unfunded special education coding status. The percentage, number of children, and 95% confidence intervals are reported in supplementary Table S-2.

access and why. Second, while the services investigated in this study are some of those available, they do not encompass all available services. For example, while we provide a rough measure of mental health need through healthcare visit information, children may present to systems through others, such as teachers, school psychologists, or community practitioners. As such, future research should include other sources of mental health diagnosis if possible. Regardless, the range of services covered by the BC Data Innovation Program is wide,[33] and should be strived for in future data initiatives. Finally, we should note limitations to the NDD definitions used in this study. In particular, while this project sought to clarify and extend previous NDD definitions,[12] further validation and development of our/this NDD definition is necessary. Furthermore, the case definition offered in this study is necessarily

Table 2
The functional limitations associated with each special education level. Codes with 33% of the group with the functional limitation are highlighted. Percentages and number of individuals for each level are reported in supplementary Table S-3, and results for each code are reported in supplementary Table S-4 & S-5.

Functional Limitation	No special education	Special Education Code			
		Unfunded	Level 3	Level 2	Level 1
Motor					**O**
Speech					
Learning		O	O	O	**O**
Social					
Sensory				O	**O**
Neuropsych					**O**
Mental Health		**O**	**O**	**O**	

simplified and does not reflect changes in limitations seen over time.

Conclusion

This study describes the diverse needs of children in special education. Our findings add to discussion on how to better identify and support needs of children with disabilities, and the need to communicate these needs across supports and services. Together this study can inform decisions on how to improve support children with disability, to facilitate their inclusion and participation in society.

Funding

This research was funded by the Canadian Institutes of Health Research (the Health System Impact Fellowship program) and the Kids Brain Health Network, a Canadian Network of Center for Excellence. While they provided funding for this project, the design of the study, data collection, analysis, interpretation, and writing of the manuscript was an independent effort of the authors. Finally, the authors would like to acknowledge the support of the CHILD-BRIGHT Network under Canada's Strategy for Patient-Oriented Research (SPOR) initiative.

Acknowledgments

This manuscript has been created from information made available through the Data Innovation Program. All inferences, opinions, and conclusions drawn in this article are those of the authors, and do not reflect the opinions or policies of the Data Innovation Program or the Province of British Columbia. The materials were developed as part of the Basic Income project, commissioned by the Ministry of Social Development and Poverty Reduction, Province of British Columbia.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dhjo.2021.101118.

Ethics statement

This study was approved through the Conjoint Faculties Research Ethics Board (CFREB) from the University of Calgary (REB 18–1633).

References

1. American Association on Intellectual and Developmental Disabilities. Intellectual disability: definition, classification, and systems of supports. In: *Classification AAHCoTa, Ed. Vol 11th Ed. Washington, DC*. AAoIaDD; 2010.
2. American Psychiatric Association. Neurodevelopmental disorders. In: *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. American Psychiatric Association; 2016.
3. Dudley C, Nicholas DB, Zwicker J. What do we know about improving employment outcomes for individuals with autism spectrum disorder? *School Publ Pol Res J*. 2015;8.
4. Nicholas DB, Zwaigenbaum L, Zwicker J, et al. Evaluation of employment-support services for adults with autism spectrum disorder. *Autism*. 2017;22: 693–702, 1362361317702507.
5. Russell MJ, Zhang Y, Cui X, Tough S, Zwicker J. *The child-to-adult transition for Albertan youth with disabilities*. Edmonton, AB: PolicyWise for Children & Families; 2019.
6. 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*. 2020;63:81–88.
7. Sullivan WF, Berg JM, Bradley E, et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Can Fam Physician*. 2011;57(5):541–553.
8. Statistics Canada. *Canadian Survey on Disability 2017*. Ottawa, ON: Statistics Canada; 2018.
9. Child and Youth Data Laboratory. *A profile of students with special needs in Alberta*. Edmonton, AB: PolicyWise for Children & Families; 2018.
10. Centers for Disease Control. Disabilities among children aged< or= 17 years–United States, 1991-1992. *MMWR Morbidity Mortality Weekly Rep*. 1995;44(33):609.
11. Lach LM, Kohen DE, Garner RE, et al. The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. *Disabil Rehabil*. 2009;31(9):741–752.
12. Arim RG, Miller AR, Guèvremont A, Lach LM, Brehaut JC, Kohen DE. Children with neurodevelopmental disorders and disabilities: a population-based study of healthcare service utilization using administrative data. *Dev Med Child Neurol*. 2017;59(12):1284–1290.
13. Diallo FB, Fombonne É, Kisely S, et al. Prevalence and correlates of Autism Spectrum Disorders in Quebec: prévalence et corrélats des troubles du spectre de l'autisme au Québec. *Can J Psychiatr*. 2017;63(4):231–239.
14. Davis NO, Kollins SH. Treatment for co-occurring attention deficit/hyperactivity disorder and autism spectrum disorder. *Neurotherapeutics*. 2012;9(3): 518–530.
15. Hogan DP, Msall ME, Rogers ML, Avery RC. Improved disability population estimates of functional limitation among American children aged 5–17. *Matern Child Health J*. 1997;1(4):203–216.
16. Einfeld SL, Ellis LA, Emerson E. Comorbidity of intellectual disability and mental disorder in children and adolescents: a systematic review. *J Intellect Dev Disabil*. 2011;36(2):137–143.
17. Zwicker J, Zaresani A, Emery JCH. Describing heterogeneity of unmet needs among adults with a developmental disability: an examination of the 2012 Canadian Survey on Disability. *Res Dev Disabil*. 2017;65:1–11.
18. Coster W, Law M, Bedell G, et al. School participation, supports and barriers of students with and without disabilities. *Child Care Health Dev*. 2013;39(4): 535–543.
19. Copley J, Ziviani J. Barriers to the use of assistive technology for children with multiple disabilities. *Occup Ther Int*. 2004;11(4):229–243.
20. Law M, Petrenchik T, King G, Hurley P. Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Arch Phys Med Rehabil*. 2007;88(12):1636–1642.
21. Hogan AJ. Social and medical models of disability and mental health: evolution and renewal. *CMAJ (Can Med Assoc J)*. 2019;191(1):E16–E18.
22. Miller AR, Masse LC, Shen J, Schiariti V, Roxborough L. Diagnostic status, functional status and complexity among Canadian children with neurodevelopmental disorders and disabilities: a population-based study. *Disabil Rehabil*. 2013;35(6):468–478.
23. Miller AR, Rosenbaum P. Perspectives on "disease" and "disability" in child health: the case of childhood neurodisability. *Front Publ Health*. 2016;4:226.
24. Ministry of Education BC. *Special education services: a manual of policies, procedures and guidelines*. Victoria, Canada: BC Ministry of Education; 2016.
25. Alberta Education. *Special education coding criteria 2008/2009*. Edmonton, Canada: Alberta Education; 2005:1911–4311.
26. Reynolds AJ, Wolfe B. Special education and school achievement: an exploratory analysis with a central-city sample. *Educ Eval Pol Anal*. 2016;21(3): 249–269.
27. Stabile M, Allin S. The economic costs of childhood disability. *Future Child*. 2012;22(1):65–96.
28. Petrou S, Johnson S, Wolke D, Marlow N. The association between neurodevelopmental disability and economic outcomes during mid-childhood. *Child Care Health Dev*. 2013;39(3):345–357.
29. CIHI. *The burden of neurological diseases, disorders and injuries in Canada*. CIHI; 2007.
30. Dudley C, Emery JCH. The value of caregiver time: costs of support and care for individuals living with Autism Spectrum Disorder. *School Publ Pol*. 2014;7.
31. Finlay B, Zwicker J. *Measure what matters. The school of public policy*; 2019. https://www.disabilitydataproject.com/. Accessed May 12, 2019. Accessed.
32. Population Data BC. *Population data BC. Population data BC*; 2021. https://www.popdata.bc.ca/. Accessed March 19, 2021. Accessed.
33. *Government of British Columbia. Data innovation program. Government of British Columbia*; 2020. https://www2.gov.bc.ca/gov/content/data/about-data-management/data-innovation-program. Accessed February 4, 2020. Accessed.
34. Columbo JA, Kang R, Trooboff SW, et al. Validating publicly available crosswalks for translating ICD-9 to ICD-10 diagnosis codes for cardiovascular outcomes research. *Circ Cardiovasc Qual Outcomes*. 2018;11(10), e004782.
35. Manitoba Centre for Health Policy. *Manitoba centre for health policy concept search*. University of Manitoba; 2019. http://mchp-appserv.cpe.umanitoba.ca/search.php?search=&type=concepts&referenceSendbackID=. Accessed.
36. Heinrichs D, Shooshtari S, Brownell M, Mills R, Stoesz B. Health and health care utilization of Manitoba children in care with and without developmental disabilities: a population-based comparative study. *J Dev Disabil*. 2018;23(2).
37. Peterson MD, Ryan JM, Hurvitz EA, Mahmoudi E. Chronic conditions in adults with cerebral palsy. *J Am Med Assoc*. 2015;314(21):2303–2305.
38. Carter EW, Hughes C. Including high school students with severe disabilities in general education classes: perspectives of general and special educators, paraprofessionals, and administrators. *Res Pract Persons Severe Disabil*. 2016;31(2):174–185.
39. Torjman S. *Disability policy: from remedies to rights*. Toronto: Canada; 2018. Maytree.

40. Kessler RC, Amminger GP, Aguilar-Gaxiola S, Alonso J, Lee S, Ustun TB. Age of onset of mental disorders: a review of recent literature. *Curr Opin Psychiatr*. 2007;20(4):359–364.
41. Penner M, Rayar M, Bashir N, Roberts SW, Hancock-Howard RL, Coyte PC. Cost-Effectiveness analysis comparing pre-diagnosis autism spectrum disorder (ASD)-Targeted intervention with Ontario's autism intervention program. *J Autism Dev Disord*. 2015;45(9):2833–2847.
42. Piccininni C, Bisnaire L, Penner M. Cost-effectiveness of wait time reduction for intensive behavioral intervention services in Ontario, Canada. *JAMA Pediatr*. 2017;171(1):23–30.
43. Russell MJ, Premji S, McDonald S, Zwicker JD, Tough S. Health care service for families with children at early risk of developmental delay: an All Our Families cohort study. *Dev Med Child Neurol*. 2019;62:338–345.
44. Morris C, Simkiss D, Busk M, et al. Setting research priorities to improve the health of children and young people with neurodisability: a British academy of childhood disability-James Lind alliance research priority setting partnership. *BMJ Open*. 2015;5(1), e006233.