

WHAT STATISTICS CANADA SURVEY DATA SOURCES ARE AVAILABLE TO STUDY NEURODEVELOPMENTAL CONDITIONS AND DISABILITIES IN CHILDREN AND YOUTH?[†]

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SUMMARY

Researchers with an interest in examining and better understanding the social context of children suffering from neurodevelopmental disabilities can benefit by using data from a wide variety of Statistics Canada surveys as well as the information contained in administrative health databases. Selective use of a particular survey and database can be informative particularly when demographics, samples, and content align with the goals and outcomes of the researcher's questions of interest.

Disabilities are not merely conditions in isolation. They are a key part of a social context involving impairment, function, and social facilitators or barriers, such as work, school and extracurricular activities. Socioeconomic factors, single parenthood, income, and education also play a role in how families cope with children's disabilities. Statistics indicate that five per cent of Canadian children aged five to 14 years have a disability, and 74 per cent of these are identified as having a neurodevelopmental condition and disability.

A number of factors must be taken into account when choosing a source of survey data, including definitions of neurodevelopmental conditions, the target group covered by the survey, which special populations are included or excluded, along with a comparison group, and the survey's design. Surveys fall into categories such as general health, disability-specific, and children and youth. They provide an excellent opportunity to look at the socioeconomic factors associated with the health of individuals, as well as how these conditions and disabilities affect families. However rich the information gleaned from survey data, it is not enough, especially given the data gaps that exist around the health and well-being of children and older youths. This is where administrative and other data can be used to complement existing data sources.

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Administrative data offer specific information about neurological conditions that won't be collected in general population surveys, given the nature of such surveys. While researchers can glean information from survey data such as functional health and disability, social inclusion or exclusion, and the role of social determinants in the lives of these children and their families, administrative data can identify rare neurodevelopmental conditions and disabilities not captured in general surveys. Analyzing information from all these sources can lead to a more nuanced understanding of the economic and social impacts, and functional limitations in daily living, that patients and their families experience with certain neurodevelopmental conditions and disabilities.

Statistics Canada surveys offer a plethora of information for researchers interested in neurodevelopmental disabilities and social determinants of health. As these surveys are national in their scope, they provide a wealth of information for statistical analysis from people across Canada. This information can be used to inform researchers, policy makers, and families of people who live with neurodevelopmental conditions and disabilities. For example, sophisticated microsimulation modelling techniques have been conducted to project the health and economic impacts from such disabilities 20 years into the future. Such projections will be vital for policy-makers tasked with designing services and programs to assist these people.

Much work remains to be done, however. Statistics Canada has already begun working on the potential for using administrative data to conceptualize childhood disability, as well as using data that has been anonymized in national administrative databases to study the health of Canada's children. These are excellent bases from which to build future research.

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NATIONAL LONGITUDINAL SURVEY OF CHILDREN AND YOUTH (NLSCY)

AGE GROUPS	FREQUENCY	DATA TYPE	STATUS	
 Cycle 1: 0-11 Cycle 3: 0-15 Cycle 5: 0-5, 8-19 Cycle 7: 0-9, 12-23 Cycle 2: 0-13 Cycle 4: 0-17 Cycle 6: 0-5, 10-21 Cycle 8: 0-7, 14-25	 1994-5...2008-09 (Biennial, 8 cycles)	 Longitudinal	 Inactive	
Utilization of health & social services* • Doctors' visits • Hospitalization • Medication use	Health utility measures* HUI	Income* Self-reported household and personal income, ratio to low income cutoff (C1-C5), income adequacy (C1-C5), general sources of income	Marital Status* Child living arrangements, PMK current marital status	Employment* PMK and spouse labour force participation
Ethnocultural background • Ethnocultural status • Immigration status • Aboriginal status	Education* Highest educational attainment (self and parent)	Personal health practices and coping skills PMK and spouse health	Social environment • Neighbourhood safety • Family functioning	Social support Social support

ABORIGINAL CHILDREN'S SURVEY (ACS)

AGE GROUPS	FREQUENCY	DATA TYPE	STATUS	
 Under 6	 2006	 Cross-sectional	 Inactive	
Utilization of health & social services* • Doctors' visits • Medication use	Health utility measures* N/A	Income* Self-reported household income	Marital Status* Child living arrangements	Employment* PMK and spouse labour force participation
Ethnocultural background N/A	Education* Highest educational attainment (PMK and spouse)	Personal health practices and coping skills PMK self-rated health	Social environment Single question on housing satisfaction	Social support Single question on satisfaction with support network

SURVEY OF YOUNG CANADIANS (SYC)

AGE GROUPS	FREQUENCY	DATA TYPE	STATUS	
 1-5, 6-9	 2010	 Cross-sectional	 Inactive	
Utilization of health & social services* • Doctors' visits • Medication use	Health utility measures* N/A	Income* Self-reported household and personal income	Marital Status* PMK current marital status	Employment* PMK and spouse labour force participation
Ethnocultural background • Ethnocultural status • Immigration status • Aboriginal status	Education* Highest educational attainment (PMK and spouse)	Personal health practices and coping skills PMK and spouse health	Social environment Neighbourhood safety	Social support Social support

ONTARIO CHILD HEALTH STUDY (OCHS)

AGE GROUPS	FREQUENCY	DATA TYPE	STATUS	
 4-11, 12-13, 14-17	 Occasional	 Cross-sectional	 Active	
Utilization of health & social services* • Doctors' visits • Hospitalization/ • Medication use Emergency room visit	Health utility measures* HUI	Income* Self-reported household income and general sources of income (request to link to tax data)	Marital Status* PMK current marital status	Employment* PMK labour force participation
Ethnocultural background • Ethnocultural status • Immigration status • Aboriginal status	Education* Highest educational attainment (PMK)	Personal health practices and coping skills • PMK and spouse functional limitations • PMK mental health	Social environment • Neighbourhood characteristics, safety • Family functioning	Social support N/A

NOTE: For surveys collected in multiple years, variables collected may not be exactly the same for all cycles. Some caution is warranted and each variable of interest should be examined separately for sample size and representativeness of the data.

NOTE: HUI is the Health Utility Index.

NOTE: PMK is the Person Most Knowledgeable about the child.

* variable that can be used in economic evaluation methodology.

INTRODUCTION

Population-based health surveys exist for multiple purposes including describing the health status of a country or jurisdiction, and reporting for policy or research purposes, such as examining health disparities or associations by socio-demographic factors such as age, gender and income. While cross-sectional surveys allow for a snapshot of the population at one point in time, longitudinal surveys allow for a video, in that events can be ordered and associations examined over periods of time.¹ This paper aims to describe the various cross-sectional and longitudinal health and health-related survey data that Statistics Canada collects, houses and makes available. In particular, we describe a variety of population-based survey data sources to inform research specifically targeting children and youth with neurodevelopmental conditions and disabilities. We conclude with a section on directions including recommendations for future survey content and development, possibilities with alternative data sources such as administrative and linked data, as well as opportunities for the use of sophisticated methods — such as microsimulation models as a policy-relevant tool to identify the impact of policy — and policy changes for children and youth living with neurodevelopmental conditions and disabilities.

UNDERSTANDING DISABILITY

The definition of disability has evolved from one based on a medical model, diagnostic or condition-specific definition, to one that is more comprehensive, focusing on functioning and the social context on one hand (see ^{2,3} for reviews) and the inclusion of both categorical and non-categorical definitions on the other.^{4,5,6} Early definitions of disability⁷ focused on the presence or absence of a specific condition (e.g., loss of vision, loss of hearing). However, with the development and acceptance of the International Classification of Functioning, Disability, and Health (ICF) framework,⁸ a specific condition is seen within the context of functional impairment (e.g., visual impairment, seeing disability) as well as within the context of facilitators and barriers to interactions with the social environment, including school, extracurricular activities, work and peers. Coupled with this is the understanding that there is an important role for social determinants such as family socio-economic factors (e.g., income, education, dual vs. single parent), support and service access, which influence health, disability and functioning.⁹

Based on a condition-specific approach, national health surveys are general in scope and do not necessarily capture neurodevelopmental conditions that are relatively rare in the general population (e.g., epilepsy, cerebral palsy, fetal alcohol spectrum disorder, autism spectrum disorder). Specific surveys, however, may be better able to target individuals with such conditions (e.g., Survey on Living with Neurological Conditions in Canada). However, to date, such condition-specific surveys have not been conducted in Canada for children and youth. For prevalence or reporting purposes, national or provincial registries such as the National Autism Surveillance System (NASS)¹⁰ may be more suitable, but to our knowledge, these do not exist for neurodevelopmental conditions specifically for children. To date, several researchers have highlighted the limitations of using a condition-specific approach and emphasized non-categorical approaches to inform public health and policy.^{11,12,13,5}

For non-categorical approaches that seek to group conditions by health consequences, rather than specific conditions, a standard definition does not exist for neurodevelopmental conditions or disabilities, nor is there consensus on which conditions should be included,^{11;12;14;15} making it difficult to estimate even basic prevalence rates. Blackburn et al.¹⁶ demonstrated that the prevalence of children with disabilities in the United Kingdom varied from five to 18 per cent depending on the definition and measure used. More recently, Morris et al.¹⁵ recommended the following definition for neurodisability, which focused on health consequences in line with a non-categorical approach:

“neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour” (pp. 1105-1106).¹⁵

Using such a non-categorical approach and data from the 2006 Participation and Activity Limitation Survey, Miller et al.¹³ estimated that five per cent of Canadian children aged five to 14 years have a disability, and of these, 74 per cent can be identified with a neurodevelopmental condition and disability. Using data from the Canadian Survey on Disability, Arim¹⁷ reported that about four per cent of youth aged 15 to 24 years have a disability; however, the prevalence of youth with a neurodevelopmental condition specifically could not be identified. These findings suggest that although estimates of child and youth disability based on survey data exist in Canada, specific identification of neurodevelopmental conditions and disabilities is not always possible.

Various theoretical approaches in the field of disability include a focus on the specific medical diagnoses (categorical approach) and a focus on the consequences of diverse health conditions (non-categorical approach), which precludes having a common identification of disability or classification of persons with disabilities. Thus, the issue of defining disability remains. Researchers’ conceptualizations and definitions depend on the study’s purpose. Based on the medical model, treatment decisions are based on specific conditions. A categorical approach may be useful to investigate such specific neurodevelopmental conditions (e.g., autism spectrum disorder); however, information from population-based surveys is often useful for policy purposes. A non-categorical approach can be useful to facilitate program planning, service delivery and policy development targeted to meet the needs of children and youth with diverse medical conditions but similar needs. Several studies^{6;13} highlight that children with different medical diagnoses (as well as their families) have common needs, such as psychosocial and rehabilitative services. Clinicians observe considerable overlap in the daily functional characteristics of children diagnosed with different medical conditions such as autism spectrum disorder, attention-deficit and hyperactivity disorders, or intellectual disability. Based on population-level data, a study by Miller et al.¹⁸ provided support for the importance of “functional characteristics” as compared with “diagnosis status” in understanding the impact of disability on child social participation, needs for services and supports, and family well-being.

STATISTICS CANADA SURVEY DATA SOURCES TO STUDY NEURODEVELOPMENTAL CONDITIONS AND DISABILITIES

Thirteen Statistics Canada surveys were identified as including information to capture child and/or youth neurodevelopmental conditions and disabilities. These surveys were classified into the following four categories based on the stated purposes of data collection:

1. General health surveys
2. Disability-specific surveys
3. Child and youth surveys
4. Other surveys

Table 1 provides detailed information about each survey, including its current status, frequency of data collection, design, description in relation to neurodevelopmental conditions and disabilities, target population, age groups covered, sampling strategy and potential definitions of neurodisabilities that the survey captured. We summarize this information for each survey and then identify the strengths and limitations of each with respect to information on neurodevelopmental conditions and disabilities for Canadian children and youth.

1. General Health Surveys

In the early 1990s, Canada, as well as other countries, (Australia, China, Italy, Germany, the Netherlands, Sweden, United Kingdom and United States) began to recognize the importance of population-based longitudinal surveys. In the fall of 1991, the National Health Information Council (NHIC)^a recommended a longitudinal national survey of population health based on the Canadian health-care system's economic and fiscal considerations and the need for information to improve the Canadian population's health status.¹⁹ In April 1992, Statistics Canada received funding from the Health Information Roadmap Initiative (Canadian Institute of Health Information, CIHI)²⁰ for the development of the National Population Health Survey (NPHS). The NPHS's mandate was to collect information on the health of the Canadian population and related socio-demographic information. Included in this was information about specific chronic conditions, functional health, restriction of activities and general health status.

Over time, the mandate of regularly collecting information and reporting on the health of Canadians became part of the objectives of the Canadian Community Health Survey (CCHS).²¹ The CCHS began in 2001 and was repeated every two years until 2005 with a mandate of creating a health information roadmap^{20;22} given a number of issues and problems with the system identified by the National Task Force on Health Information.²² Beginning in 2007, data for the CCHS have been collected annually instead of every two years for two main reasons: (a) to allow for varied survey content and to increase the frequency of data releases, and (b) to ensure better use of operational resources. In 2012, the CCHS began a major redesign to review the sampling methodology, adopt a new sample

^a NHIC was one of the federal-provincial committees launched by the Conference of Deputy Ministers of Health to improve health information development.

frame, modernize the content, and review the target population, which was completed and implemented for the 2015 cycle.^b

Both the NPHS and the CCHS include few chronic conditions that can be identified as a neurodevelopmental condition. However, both surveys collect information on restriction of activities and functional status (optional content in CCHS), which may be used as a proxy for disabilities but not necessarily for a comprehensive identification of neurodisabilities. Thus, these general health surveys are limited in their ability to capture neurodevelopmental conditions, but it may be possible to examine some information about functional status which may be of interest to researchers.

2. Disability-Specific Surveys

Statistics Canada has been collecting data on disability for more than 30 years via a number of surveys. From 1983 to 2006, three successive surveys were conducted to collect data related to disability: the Canadian Health and Disability Survey (1983, 1984), the Health and Activity Limitation Survey (1986, 1991), and the Participation and Activity Limitation Survey (2001, 2006). The Canadian Health and Disability Survey^c was conducted as a supplement to the Labour Force Survey (LFS; Statistics Canada, 1989). The Health and Activity Limitation Survey (HALS) was a post-censal survey used to identify the number and distribution of persons with disabilities (both children and adults) in Canadian households²³ as well as non-penal institutions.^{d,24} In 2001, the HALS was renamed the Participation and Activity Limitation Survey (PALS)²⁵ to reflect a new focus on the social participation of persons with limitations. The PALS was specifically designed to identify individuals (both children and adults) whose day-to-day activities may have been limited because of a health condition or problem.²⁵

In 2012, the PALS was replaced by the Canadian Survey on Disability (CSD),²⁶ which was developed as part of the New Disability Data Strategy launched by Employment and Social Development Canada and provides the most recent data related to disability.¹⁷ The CSD incorporates a more complete social model of disability, although it did not include children and youth younger than 15 years of age. The definition of disability in the CSD differs from the previous disability surveys. Specifically, respondents who indicated that they had some type of impairment and some difficulty with certain tasks, but were not limited in their daily activities, were not considered to have a disability in the CSD.²⁶ For example, if individuals reported having a lot of difficulty walking but that their daily activities were rarely limited, they would have been considered as having a disability in PALS but not in the CSD. Exceptions to this include disabilities due to mental health, pain and memory, for

^b The main objective of the CCHS remains to collect information related to health status, health-care utilization and health determinants for the Canadian population in three components: the common content, the optional content and the rapid response content. The common content is collected from all respondents. The optional content aims to respond to changing policy needs at the health region level. This content is uniquely prepared for each province and varies from year to year. The rapid response content is collected for organizations that are interested in an emerging or specific population health issue. Finally, in order to allow for regular reporting and timely responses to information to fulfil stakeholders' needs, the CCHS has been supplemented by other specifically themed cross-sectional content, such as the CCHS-Nutrition and the CCHS-Mental Health.

^c The Canadian Health and Disability Survey was not included in detail in this review because of the age of the survey and changes in the definition of disability over the past three decades.

^d The Health and Activity Limitation Survey: Institutional Component was discontinued after the 1991 reference period.

which associated daily activity limitations were considered a disability in both surveys. For these conceptual and other methodological reasons, comparisons of disability data among the HALS, the PALS and the CSD are not recommended.^{25;26}

Other disability-specific surveys also exist. For example, the Survey on Living with Neurological Conditions in Canada (SLNCC)²⁷ was conducted in 2011 to collect information about Canadians' experiences with chronic neurological conditions.^e The SLNCC focused on youth and adults aged 15 and over and did not include children under the age of 15. Sponsored by the Public Health Agency of Canada, the SLNCC focused on 18 chronic neurological conditions and provided information about their impact on quality of life, work and general well-being for individuals living with these conditions, associated costs, and the impact of providing assistance on people caring for individuals living with these conditions. Thus, the survey reported on various factors that were associated with the health of individuals living with neurological conditions, their families and caregivers.

Overall, all disability-specific surveys except the SLNCC define disabilities based on individuals' difficulties in their daily activities because of a condition or a health problem. Yet, each survey has its own conceptualization of disability and therefore comparisons among surveys are not recommended. Both the HALS and the PALS (but not the CSD) collected information about neurodevelopmental conditions^f and HALS, PALS and CSD ask about activity limitations in daily activities whereas activity limitations in the SLNCC are linked to the presence of specific conditions only (18 neurological conditions). Finally, child populations are included in the HALS and PALS but excluded from the CSD and the SLNCC.

3. Child and Youth Surveys

In the 1980s, population-based surveys on children and youth were limited (see Montreal Longitudinal and Experimental Study (MLEs)²⁸ and the Ontario Child Health Study (OCHS)²⁹ for exceptions). However, given the idea that a society's future lies in the children and youth of the present, understanding the development and life experiences of children and youth became important in learning about that future.^{30;31;32} In fact, the 2000 Federal-Provincial-Territorial Health Care Accord included an agreement that provided funding for early childhood development supports and services.³³ To this end, longitudinal data were seen as essential to monitor children's and youth's development, changes over time, and the role of the social environment in children's development. The National Longitudinal Survey of Children and Youth (NLSCY)³⁴ studied Canadian children, following their development and well-being from birth to early adulthood. The survey was designed to collect information about factors that influence a child's social, emotional and behavioural

^e The purpose was to address knowledge gaps about individuals living with neurological conditions as well as their families and caregivers.

^f The list of chronic conditions included slightly different health problems. For example, autism and fetal alcohol syndrome were asked about in the PALS but not in the HALS.

development, and to monitor influences on the child's development. Included in this was information about specific chronic conditions, functional health, activity restrictions and general health status.⁸

The original NLSCY also included the Survey of Northern Children, which collected information on children living in northern Canada. In 2006, this content was incorporated into the Aboriginal Children's Survey (ACS),³⁶ which aimed to provide information on the health and development of Aboriginal children (First Nations, Inuit, Métis) living off reserve and under the age of six years, and the social and living conditions in which they learn and grow across Canada. The ACS included information about specific chronic conditions and a single item on activity limitation.

Inspired by the NLSCY, in 2010, a cross-sectional survey, the Survey of Young Canadians (SYC)³⁷ was conducted to provide nationally representative indicators on child development, including child health and well-being. The target population included children aged one to nine, living in the 10 provinces. However, to reduce response burden, only one child was selected per household for the sample, which resulted in a relatively small sample size. The SYC also focused on specific chronic conditions, including neurodevelopmental conditions, as well as activity restrictions.

McMaster University sponsored the Ontario Child Health Study (OCHS), which was conducted to shed light on associations among child mental health conditions, chronic health conditions, and social and academic functioning. Specifically, the OCHS focused on specific developmental conditions, a few chronic conditions and functional health status. Subsequent to two earlier cycles of data collected on children in Ontario (1987, 2000), a 2014 OCHS was collected with a mandate of studying the physical and mental health of Ontario children and youth aged four to 17. Overall, it is anticipated that the results from the 2014 OCHS will help increase our understanding of children's mental health as well as provide data to help support the development of programs and policies for children and youth in Ontario.

In summary, all four child and youth surveys described above collect information about chronic conditions, including neurodevelopmental conditions. All but the OCHS also ask about activity limitations which vary from one survey to another. Thus, all four child and youth surveys can provide information in relation to child and youth neurodevelopmental conditions and all but the OCHS can measure child and youth neurodevelopmental disabilities.

⁸ The NLSCY consisted of several longitudinal and cross-sectional samples, beginning in 1994-95 (Cycle 1) and ending in 2008-09 (Cycle 8).³⁵ The survey covered a comprehensive range of topics including child health, physical development, and learning and behaviour, as well as information on the social environment (e.g., family, friends, schools and communities). The household collection included: (a) a parent questionnaire that collected information about the person most knowledgeable (PMK) about the child and his/her spouse/partner, (b) a general questionnaire that collected socio-economic information about the PMK and his/her spouse/partner, and (c) a child questionnaire that was completed for selected children in the household.³⁴ For some cycles, there was also information collected in school that included: (a) a teacher questionnaire that collected information about the child in school, including the characteristics of the class and the teacher's instructional practices, (b) a principal questionnaire that focused on the school environment, and (c) a math computation test that was administered to the child by his or her teacher.³⁴

4. Other Surveys

Three other active surveys are worth highlighting because of their content relevant to Canadians' health and well-being: the General Social Survey (GSS),³⁸ the Longitudinal and International Study of Adults (LISA),³⁹ and the Aboriginal Peoples Survey (APS).⁴⁰

The GSS program was established in 1985 and was designed as an annual cross-sectional survey, with each survey covering one topic in-depth across the 10 provinces.⁴¹ Current GSS topics include caregiving, families, time use, social identity, volunteering and victimization. A specific social policy topic is usually repeated every five years. For example, both Cycle 23 (2009)³⁸ and Cycle 28 (2014)⁴² of the GSS focused on Canadians' safety, to better understand how Canadians perceive crime and the justice system and to gather information on experiences of victimization.^h Notably, Cycle 28 (Victimization) for the first time, and subsequently, Cycle 29 (Time Use) included the Disability Screening Questions (DSQ), a measure of disability that does not include a specific focus on neurodevelopmental conditions or disabilities.

The LISA was initiated based on a longitudinal surveys conference in January 2006 hosted by Statistics Canada, the Social and Humanities Research Council of Canada and the Canadian Institute of Health Research. Longitudinal survey data collecting information on the adult population for labour and income, family, human capital development and health domains were identified as an important data gap in Canada.⁴³ Following this conference, Statistics Canada received funds from the Policy Research Data Gaps fund to support the development of a pilot survey, the Canadian Household Panel Survey Pilot (CHPS-Pilot), in partnership with Human Resources and Skills Development Canada (HRSDC) and the Canadian academic community.⁴³ For the purposes of fieldwork, the name of this pilot was the Living in Canada Survey: Pilot, which became LISA in 2012. The LISA aims to shed light on Canadians' lives in order to understand, for example, how families cope with complex issues such as poor health, what services they require, and information needs to support decision-making about today and the future. In the LISA's first wave (2011-2012), coverage included the population living in the 10 provinces, plus their future children. It should be noted that data collected through the LISA are linked to tax files (e.g., T1 Personal Master File, T4 Summary and Supplementary Files, Pension Plan in Canada Files, and the T1 Family File), as well as to the Immigration Database.³⁹ Information from tax files is particularly important in the context of examining social determinants in relation to neurodevelopmental conditions and disabilities.

The APS was first conducted in 1991 based on the recommendation of the Royal Commission on Aboriginal Peoples (RCAP).⁴⁰ Funded by three federal departments — Indigenous and Northern Affairs Canada (formerly Aboriginal Affairs and Northern Development Canada), Health Canada, and Employment and Social Development Canada (formerly called Human Resources and Skills Development Canada) — the APS is a national survey of First Nations people living off reserve, Métis and Inuit, aged six years and over. The survey aims to provide information on the economic and social conditions

^h The objectives of the GSS program are to provide information on specific social policy topics as well as gather information on social trends with a snapshot focus on the living conditions and well-being of Canadians aged 15 and over.⁴¹

of Aboriginal people in Canada to identify their needs and to focus on issues such as education, employment, health, language, income, housing and mobility. The most recent version was conducted in 2012.⁴⁰

Overall, the GSS, LISA and APS vary in their ability to provide information on neurodevelopmental conditions and disabilities, often depending on the cycle of the survey. While the GSS and the LISA include a measure of disability based on individuals' difficulties in their daily activities due to a specific condition or a health problem, without indicating a specific health condition, only the APS collects information about chronic conditions, including neurodevelopmental conditions. However, it does not collect information about activity limitations except for those due to asthma.

In summary, various survey data exist at Statistics Canada to enable the study of neurodevelopmental conditions and disabilities among children and youth. Some of these surveys are general in focus while others are more specific. Some are ongoing while some are not, and some focus on specific subpopulations.

HOW ARE NEURODEVELOPMENTAL DISABILITIES DEFINED IN STATISTICS CANADA SURVEYS?

When a specific subpopulation is of interest, the first important factor to consider when selecting the most appropriate source of data should be the definition of neurodevelopmental conditions or disabilities (see Table 1). One way to do so is based on a categorical approach, such as defining such conditions or disabilities based on the presence of a specific health condition. Most of the surveys reviewed above include a list of diagnosed chronic conditions from which one or more specific neurodevelopmental conditions can be selected. However, chronic conditions lists are limited and not usually comprehensive with respect to the neurological conditions included. For instance, some neurodevelopmental conditions, such as epilepsy, are included in most survey chronic condition checklists (e.g., CCHS, NPHS, NLSCY, ACS), whereas other neurodevelopmental conditions, such as a learning disability or autism, are not always included (e.g., autism is only asked of children aged three to seven and 14-15 years old in NLSCY Cycle 8 (2008-09)). Even when chronic conditions are included, the prevalence reported by respondents may be too low to meet reporting guideline criteria. Chronic condition checklists often ask for diagnosed chronic conditions which may be problematic in that child diagnoses are obtained over time and asking about specific diagnosed conditions may underestimate actual prevalence. Further, due to barriers to health-service access, some children or youth, such as those living in rural and remote communities, may be disadvantaged in terms of service access and obtaining a diagnosis.⁴⁴

The inclusion of specific neurological conditions in the chronic condition list is not necessarily an indication of data usability for the study of neurological conditions. Sufficient sample size, in particular for rare conditions, acceptable response rates and data reliability need to be examined and assessed prior to use. Users should be particularly cautious when determining the prevalence of neurodevelopmental conditions based on survey data. For example, while it may be feasible to determine the prevalence of children with epilepsy using data from the NLSCY that is a nationally representative survey of

Canadian children and youth, information in the CSD may not be meaningful to determine prevalence due to the flow of the survey questions. In the NLSCY, the epilepsy item asks about a long-term condition diagnosed by a health professional. In contrast, in the CSD, respondents report on the main medical condition that causes the respondent the most difficulty or limitation to their daily activities. Thus, those who have epilepsy might report difficulty or limitations in activities based on another medical condition (e.g., cerebral palsy) and they would therefore not be classified as having epilepsy. Therefore, determining the prevalence of epilepsy in the population based on the CSD would be inaccurate.

In addition to these drawbacks, categorical or condition-specific measures in isolation do not reflect current theoretical frameworks because they do not capture the aspect of functional limitations, nor do they capture undiagnosed conditions or the large number of rare conditions not included in such lists that have similar consequences for children. In contrast, non-categorical approaches offer a non-condition-specific conceptual framework to identify children with neurodevelopmental conditions and disabilities. This approach stems from the idea that regardless of the specific condition, children with health problems such as neurodevelopmental conditions share similarities in the consequences of their conditions. In comparing two children, one may have a diagnosis of epilepsy and another an undiagnosed neurological condition. Both children may require frequent visits to the doctor's office, both may require assistive devices, and both may require prescription medications. Using a non-categorical approach, these children can be grouped together by virtue of similar consequences of related conditions. A non-categorical approach is particularly useful for program planning, service delivery and policy development, where program or policy decisions are made on the basis of health consequences and services for large groups or populations. A non-condition-specific, non-categorical definition includes grouping similar conditions such as specific neurodevelopmental conditions and disabilities to focus on functional abilities rather than on any one specific condition.

Research has shown that children with neurodevelopmental conditions and disabilities are at risk for activity limitations and reduced participation in daily activities.⁴⁵ Thus, an important dimension that should be included in a meaningful definition of neurodevelopmental conditions and disabilities is restriction of activities and the associated social context. For example, the NPHS and CCHS general health surveys and the NLSCY child survey include items that ask whether a physical or mental condition or a health problem reduces the amount or the kind of activity the child can do in different social environments, such as at home, at school and at play. In contrast, disability-specific surveys such as the PALS and the CSD ask whether the individual has any difficulty seeing, hearing, walking, learning or remembering because of a condition or a health problem (and if so, how much difficulty) to determine the presence of restriction in activities. The distinction is important to highlight because of the conceptual differences. General health surveys focus on specific social environments in which individuals may have activity limitations (e.g., home and school) whereas disability-specific surveys concentrate on the functional domains in which individuals experience difficulties (e.g., walking and learning). The 2011 SLNCC and to some extent the CSD are unique because these surveys examine restriction of activities with a focus on the social context. For example, in the SLNCC, individuals indicate whether their condition limits their educational or job opportunities and how much they feel that their condition affects their lives. In the CSD, respondents indicate how often the condition limits their daily activities.

In addition to a list of chronic conditions and activity limitations, some surveys also include instruments to measure functional health status. Since 1990, the standard instrument in Statistics Canada's health surveys has been the widely used Health Utility Index (HUI), which assesses health status and health-related quality of life.^{46,47} The HUI3 classification system includes eight attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain. Each attribute has five or six levels of ability/disability. (For additional information about the scoring of HUI, readers should refer to the survey user guides).

Survey-specific issues need to be recognized when using measures like the HUI, such as the order/placement of the items in the survey. For example, while the NPHS, NLSCY, OCHS, PALS and SLNCC ask all HUI items in one module of the survey, in the 2014 CCHS, the HUI items are asked in two separate modules. Specifically, the Pain and Discomfort module (HUP) includes three HUI questions and is part of the core content asked to all survey respondents. However, the seven other attributes are included in the HUIⁱ module and are optional content that each province may or may not select. Thus, users should take caution that the HUI may not be included for all respondents. Further, although the HUI was asked of children aged four to 11 years in the first cycle of the NLSCY, the HUI was only included for children aged four to five years in subsequent cycles of the NLSCY. Finally, not all surveys include the HUI or other measures of functional health (e.g., SYC).

As mentioned previously, definitions of disability also vary among disability-specific surveys. For example, PALS defined disability as “an activity limitation or participation restriction associated with a physical or mental condition or health problem” (p.57).²⁵ This definition is based on the ICF framework^k that conceptualized disability as the relationship among body structures and functions, daily activities and social participation, while recognizing the role of environmental factors.⁸ This definition of disability is based on both a medical and a social model of disability.

Since 2012, a new instrument named the Disability Screening Questions (DSQ) has been introduced in several Statistics Canada surveys. The DSQ's intention is to move towards a social model of disability that denotes that the presence of a condition or difficulty alone is not sufficient for identifying a disability — a limitation in daily activities must also be stated.²⁶ Thus, based on a social model of disability, the DSQ measures both the type and severity of disability by assessing how often individuals' daily activities are limited by long-term conditions, health problems and task-based difficulties. It should be noted that the DSQ was specifically developed for the measurement of disability among adults but not among children.²⁶ The DSQ was first introduced in the CSD and subsequently added to other surveys including the 2014 LISA, the 2014 GSS and the 2017 APS.

It should also be noted that both the PALS and the CSD collected information about the main medical conditions that cause the most difficulty or limitation to daily activities. Statistics Canada coded write-in responses to the International Classification of Diseases,

ⁱ In 2009-2010, the HUI module is also asked to all respondents as part of the theme content.

^j It should also be noted that the PALS used different criteria to identify disabilities in children (ages zero-14) and adults (15 years or older).^{48,49}

^k The conceptual framework of the ICF is based on a biopsychosocial model of health. The ICF is a widely accepted classification system for coding and documenting health and disability.⁸

10th Revision (ICD-10) to better organize the data and to facilitate researchers' and analysts' examination of medical conditions. Specifically, up to three main medical conditions in the 2006 PALS and up to two main medical conditions in the 2012 CSD are recoded into ICD-10 codes. Initially, neither PALS nor CSD was intended to be linked to administrative data sources. However, with the increased use of administrative data to study child and youth health, there has been an attempt to examine administrative-based diagnostic codes in survey data.

To date, few researchers^{45,13} have used ICD-10 codes in addition to chronic conditions and functional limitations to identify neurodevelopmental conditions and disabilities. Our recent findings⁵⁰ have shown that although there is high agreement between reports of chronic conditions and corresponding ICD-10 codes (e.g., a high percentage of children reported to have attention deficit disorder as a chronic condition also report a main condition related to a disturbance of activity and attention (ICD-10 code)), other health problems capture different groups of children based on the approach taken. This discrepancy may be due to various reasons, including the fact that the ICD-10 codes are derived based on the main medical condition(s) that cause the most difficulty or limitation to daily activities (i.e., more severe conditions are captured by the ICD-10 codes). In other words, because ICD-10 codes reflect something more than just the presence of a chronic condition in the PALS survey, it is difficult to draw a valid conclusion with regards to agreement between survey and administrative data. More research is needed to further explore whether a combination of both administrative and survey data provides the most useful and meaningful identification of children with neurodevelopmental conditions and disabilities.

WHAT OTHER INFORMATION SHOULD BE CONSIDERED WHEN SELECTING A STATISTICS CANADA SURVEY TO STUDY CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES?

Four additional criteria may influence the choice of a particular survey data set to study child and youth with neurodevelopmental conditions or disabilities (see Table 1). Two of these criteria are related to the survey's methodology, including the respondents' age range and the survey design. The other two criteria are related to the survey's content, that is whether special populations (e.g., immigrants, Aboriginal people) are included in the survey, and the presence of a comparison group (i.e., persons without disabilities).

An important point to consider in selecting a survey data source to study children and youth with neurodevelopmental conditions or disabilities is the age range of a particular survey's respondents. The population for general health surveys such as the NPHS and the CCHS usually includes those aged 12 years and over. The disability-specific surveys vary in age range. For example, the PALS includes both child (zero-14 years) and adult versions (15 years or older) whereas more recent disability-specific surveys such as the SLNCC and the CSD include respondents aged 15 years and over only. Similarly, other surveys such as the LISA and the GSS also cover respondents aged 15 years and over. If child neurodevelopmental condition and disability are of interest, then there are fewer options. The national SYC includes children aged one to nine years, whereas the provincial OCHS includes children four to 17 years old. The NLSCY provides the largest age range as the original cohort was zero- to 11-year-olds in Cycle 1. In Cycle 4, the sample is comprised of

zero- to 17-year-olds, including children from the original cohort and zero- to one-year-olds added in subsequent cycles (Cycles 2-4). Between Cycle 5 and Cycle 8, an early childhood cohort (zero to five years) as well as follow-up of children from the original cohort (until they become 25 years old in Cycle 8) was included. Newborns in Cycle 3 and Cycle 4 were followed up until they were eight to nine and six to seven years old, respectively, in Cycle 7.

Along with age range, it is also important to consider the survey design. Information from cross-sectional surveys provides timely information at a single glance, whereas longitudinal surveys allow for an examination of trends and changes over time. Of the 13 surveys this paper reviews, three have a longitudinal design: a general health survey, the NPHS, that started in 1994-95 and ended in 2010-11 (Cycle 9); a child survey, the NLSCY, that started in 1994-95 and ended in 2008-09 (Cycle 8); and an additional survey, the LISA, that started in 2012 and is still active (biennial). However, since LISA 2014 was the first wave that included the DSQ as a measure of disability, longitudinal information on disability based on the DSQ will not be available until subsequent waves are available. Although somewhat dated (both surveys ended in 2008), both the NPHS and the NLSCY offer a wide range of options to identify neurodevelopmental conditions and disabilities. Both surveys include a list of chronic conditions related to neurodevelopmental conditions and disabilities, questions about activity limitations and the HUI instrument. The ultimate selection of the NPHS or the NLSCY lies within the age range of interest. As mentioned above, the NPHS includes individuals 12 years or older, whereas the NLSCY includes children zero to 11 years old at the survey's beginning.

Despite the availability of longitudinal data, few studies have examined the stability of neurodevelopmental conditions or disabilities over time. In a previous study that examined psychosocial functioning in children with neurodevelopmental disorders and externalizing behaviour problems,⁵¹ we found high stability (96 per cent) over a two-year period (i.e., between Cycle 1 and Cycle 2) for neurodevelopmental disorders that were identified using a list of chronic conditions from the NLSCY. It should be noted that stability could not be examined in subsequent cycles because of the lack of information on the variables of interest, including HUI. Thus, we highly recommend that analysts interested in longitudinal data conduct validity checks of their selected definitions.

Another important point to consider in selecting a survey data source is the specific population that can be studied. For example, the HALS, PALS and CSD are post-censal surveys aimed at targeting those with activity limitations, the ACS provides national data on Aboriginal children younger than six years of age and the APS collects national data from Aboriginal people six years and older. To study immigrant populations, most of the surveys reviewed in this paper provide data at the national level. However, sample size, non-response and reliability should be examined prior to subgroup analyses (such as by age, sex and other demographic characteristics).

One particular strength of using population-based survey data, compared to data from clinical studies, is the availability of a comparison group in many population-based data, which allows for a contextualization of findings (e.g., children with disabilities as compared to children without disabilities). It should be noted that different surveys may provide different or no comparison groups (e.g., PALS, CSD). For this reason, it is important to know about a survey's sampling strategy and design. For example, most general health surveys such as the NPHS and the CCHS are conducted in the provinces and territories and

use a sample design based on the Labour Force Survey (LFS).^{21,19} The LFS excludes persons living on reserves and other Aboriginal settlements in the provinces, full-time members of the Canadian Armed Forces, the institutionalized population, and households in extremely remote areas with very low population density; these exclusions represent less than two per cent of the Canadian population.⁵² In contrast, disability-specific surveys such as the PALS and the CSD include individuals who reported an activity limitation or a participation restriction related to a health condition based on responses to the Census of Population or the National Household Survey; the former enumerates the entire Canadian population, and the latter covers all persons who usually live in Canada. As a result, the identified populations in these disability-specific surveys are a subset of the surveyed population who are themselves a subset of the general population. Therefore, comparison groups in the general health surveys differ from comparison groups in disability-specific surveys.

In summary, there are various criteria to consider when selecting the most appropriate source of survey data to study neurodevelopmental disabilities, including the definition(s) of neurodevelopmental conditions and disabilities of interest, the age group included in the survey sample, the survey design, the inclusion of special populations and a comparison group. We present details in Table 1 to provide readers additional guidance.

SOCIAL DETERMINANTS OF NEURODEVELOPMENTAL DISABILITIES

The important role of economic, social and family factors on children and adults with disabilities is well-documented.^{16,53;54;55} Denny and Brownell⁵⁶ provide an overview of various social determinants of child health and development. According to Leitch,⁵⁷ “a look through the lens of social determinants of health tells us a lot about our children.” To this end, the Health Economics and Social Determinants of Health (HE-SDOH) project focuses on the social context of children with neurodevelopmental conditions and disabilities.⁵⁸ A strength of population-based data as compared to smaller scale clinical studies is that a wide range of social determinants variables are often available for analysis. In addition, the larger sample sizes from population-based data allow for an examination of the interactions among social determinants, which is often not possible with smaller clinical samples. Understanding how different social determinants are associated with neurodevelopmental conditions or disabilities is essential for policy and program planning and is at the core of HE-SDOH project.

Table 2 provides a summary of the social determinants variables we describe below.

The utilization of health and social services is incorporated in most general health surveys such as the NPHS and the CCHS and includes questions about the use of health services, such as doctor’s visits, hospitalization and medication use. Disability-specific surveys vary in their coverage of health service use. For example, while the HALS and the PALS also include questions about doctors’ visits, hospitalization and medication use, the CSD and the SLNCC only ask about medication use. Child and youth surveys also cover doctor’s visits and medication use but few of them (NLSCY, OCHS) ask about hospitalizations. Other surveys such as the GSS and the LISA do not include health and social service use.

Most surveys lack information about social services use by families of children with neurodevelopmental conditions and disabilities. Future surveys may wish to focus on this area to identify facilitators and barriers to access to social services.

Health utility measures are of interest to provide information about functional health in addition to being considered as a key economic evaluation variable, and are usually included in general health surveys. Health utility measures offer summary scores of health-related quality of life (HRQL) for health states. Utility scores of overall HRQL are also used in cost-utility and cost-effectiveness analyses. Both the NPHS and the CCHS include the HUI, and the Short Form Health Survey (SF-36) was optional content in some cycles (for some provinces) of the CCHS. Among the disability-specific surveys, the PALS and the SLNCC included HUI, although the CSD, the most recent survey on disability, does not include any measure of health utility. Among child and youth surveys, the NLSCY and the OCHS are the only surveys that include the HUI. No other surveys cited in the present review include a measure of health utility.

Income and marital status are variables included in all Statistics Canada's surveys. However, more specific indicators such as measures of income adequacy and assets may exist in some (e.g., low income status in the CSD and NLSCY) but not all surveys. None of the 13 surveys reviewed here included information about assets, which is of interest to the HE-SDOH project, but most surveys include information about sources of income. Additionally, while information on employment insurance as a source of income is collected in most surveys (e.g., NPHS, CSD, NLSCY, APS and GSS), Canada or Quebec Pension Plan disability benefits as a source of income are generally only collected in disability-specific surveys (e.g., PALS and CSD). Information on disability benefits can also be obtained in the LISA through record linkage to tax files. Readers may refer to user guides of the specific surveys for additional information.

Education and employment variables are also generally included in population-based surveys although different surveys may provide different indicators of educational achievement, employment and working conditions. For example, while most surveys include the respondent's highest level of educational attainment and employment status, more specific education (e.g., school attendance or performance) or employment (e.g., full-time vs. part-time employment) indicators may not always be included. As an example, general health surveys (e.g., NPHS, CCHS) ask about school attendance and the nature of labour force participation but not about school performance or progression through grades. In disability-specific surveys (e.g., PALS, CSD), information about school attendance and employment status are asked but details about school performance and parent employment status are not (even though the CSD includes many questions on education and employment experiences including barriers and accommodations in these areas).

Ethnocultural background plays a key role as a social determinant of health.⁵⁹ Social determinant information related to culture, including ethnocultural status, immigration status, and Aboriginal status are usually collected in most Statistics Canada's surveys due to the population-based nature of these surveys (i.e., nationally representative). However, most surveys reviewed in this paper exclude individuals living on First Nations reserves or Crown lands as well as residents of some remote regions, and several surveys do not collect data in the territories (e.g., NPHS, SYC, GSS, LISA). Thus, readers are encouraged to verify the survey's target population before deciding whether meaningful analyses can

be conducted for social determinants related to culture and ethnicity. For example, the ACS, rather than the NLSCY, would provide a representative sample of Aboriginal children in Canada. In a similar vein, a survey sampling strategy based on the Census may provide a more representative sample of immigrants compared to a survey sampling strategy based on the LFS. Thus, if ethnocultural background is of interest, sample size, non-response and reliability should be examined prior to subgroup analyses.

Personal health practices and coping skills as social determinants of health are also of interest. For example, stress is usually covered in both general health as well as disability-specific surveys (except the CSD). A measure of coping skills is generally not collected in any of the 13 surveys reviewed, although some cycles of the NPHS and the CCHS cover coping with stress. The health of caregivers of children with neurodevelopmental conditions and disabilities can be examined using child and youth surveys such as the NLSCY, the ACS, the SYC and the OCHS as well as the PALS (but not the CSD). Information on persons with disabilities as a caregiver of a child can be derived from general health surveys such as the NPHS and the CCHS, as well as other surveys such as the GSS and the LISA. Notably, Cycle 26 of the 2012 GSS focused on caregiving and care receiving.^{60;61}

Social environment determinants such as family environment, housing and neighbourhood characteristics are also included in some surveys. For example, within the general health surveys, the NPHS does not include any questions on family, housing or neighbourhoods, although the CCHS includes questions about type of housing and characteristics of neighbourhoods (but not about family environment). Disability-specific surveys such as the PALS and the CSD do not include any information on housing and neighbourhood but include some questions on family environment in the form of help received from family. Child and youth surveys such as the NLSCY and the OCHS appear to be more inclusive of family environment and neighbourhood factors in order to examine associations with child and youth development and well-being. The NLSCY, but not the SYC, includes some questions on housing. In general, social environment determinants are not covered in other surveys (e.g., LISA).

Social support is often examined as an important social determinant in the context of disability. Although a module on social support was included in both general health surveys (NPHS and CCHS) as well as earlier disability-specific surveys such as the PALS and the SLNCC, perceived social support was not included in the recent CSD. Social support is also a topic of interest in most child and youth surveys (e.g., NLSCY, SYC) but not in the OCHS. The ACS includes a single question on satisfaction with one's support network. Other surveys may focus on social support depending on the specific social issue of interest in that cycle (e.g., GSS). Finally, the LISA does not include information on social support, although the APS includes an item on perceived community support.

CONCLUSION

Various survey data are available at Statistics Canada to study neurodevelopmental conditions or disabilities for children and youth. However, there are several important criteria to consider when selecting an appropriate source of survey data for secondary data analyses, including the definition(s) of neurodevelopmental conditions and the disabilities

of interest, the age group included in the survey sample, the survey design, the inclusion of special populations and a comparison group, and the social determinants of interest. Survey data offer significant opportunities to examine social determinants of health and the complex interactions among various factors for individuals with neurodevelopmental conditions and disabilities and their families. While research in this area has begun,^{62;63;64} much work remains to gain a better understanding of the social context of children with neurodevelopmental conditions and disabilities, and their families.

Currently, there is a data gap on child and youth health and well-being, including neurodevelopmental conditions and disabilities, along with factors influencing child and youth development. Administrative health data can provide information about specific neurodevelopmental conditions that may not be captured in survey data. Survey data can add complementary information such as functional health and disability, social participation and inclusion, as well as factors that can be considered in studies of social determinants. However, administrative data linked to survey data have the added advantage of the identification of rare neurodevelopmental conditions and disabilities together with data to delineate the role of social determinants in the lives of children with neurodevelopmental conditions and disabilities, and their families.

Information from survey data also allows opportunities for the use of sophisticated methods such as microsimulation models as a policy-relevant tool to identify the impact of policy and policy changes for individuals living with neurodevelopmental conditions and disabilities. For example, Finès et al.⁶⁵ have recently described the development and performance of microsimulation models of seven neurological conditions, including cerebral palsy and epilepsy, to project the health and economic impacts of neurological conditions over the next 20 years. Future research can integrate recent Canadian data on child and youth neurodevelopmental conditions and disabilities along with various social determinants to identify the health and economic impacts of living with these conditions and disabilities.

There are various other benefits of using Statistics Canada survey data to study child and youth neurodevelopmental conditions and disabilities. First, survey data are often nationally representative, collecting information from a large number of individuals across Canada. Second, a broad range of data (e.g., education, income, health) can be collected given the topics of interest in a particular survey. Third, advanced statistical techniques can be utilized to analyze survey data, including the ability to analyze multiple variables and produce generalizable robust findings. Overall, survey data offer a good opportunity to study neurodevelopmental conditions and disabilities in children and youth as well as explore the role of social determinants associated with these conditions and disabilities.

It was beyond the scope of the present paper to describe in detail the many other excellent provincially linked administrative data bases such as the Institute for Clinical Evaluative Sciences (ICES), the Population Health Research Data Repository housed at the Manitoba Centre for Health Policy, and Population Data BC, as well as national registries such as the Canadian Chronic Disease Surveillance System (CCDSS), a collaborative network of provincial and territorial surveillance systems which is supported by the Public Health Agency of Canada. These should be considered as additional sources for information

about children and youth with neurodevelopmental conditions and disabilities and would be a fruitful topic for future reviews. Work at Statistics Canada has begun to examine the possibilities of using administrative data for conceptualizing child disability^{62;66;67} as well as data linked to anonymized national administrative data^{68;69;70} to study child health.

TABLE 1 STATISTICS CANADA DATA SOURCES ON NEURODEVELOPMENTAL CONDITIONS AND DISABILITIES

Data source	Status	Frequency	Type of data	Description	Target population	Age groups	Sample	Potential definitions of neurodisabilities	Special populations	Comparison group
General Health Surveys										
National Population Health Survey (NPHS)	Inactive	1994-95...2010-2011 (9 cycles); Cycles 1-3 have cross-sectional and longitudinal components, Cycles 4-9 longitudinal only	Longitudinal	The NPHS is a general health survey that is limited in its ability to identify children and youth with neurodisabilities due to the age range of the sample and potential definitions of neurodisability.	The target population includes household residents in the ten Canadian provinces excluding persons living on Indian Reserves and Crown Lands, residents of health institutions, full-time members of the Canadian Forces Bases and some remote areas in Ontario and Quebec.	12+	The NPHS employed a stratified two-stage sample design (clusters, dwellings) based on the Labour Force Survey (LFS) in all provinces except Québec, where Santé Québec's design for the 1992/1993 Enquête sociale et de santé (ESS) was used.	Chronic conditions (epilepsy, effects of stroke) Health Utility Index Restriction of activities	Immigrant ^a Aboriginal ^a	General Canadian Population
Canadian Community Health Survey (CCHS)	Active	Annual (core) + special topics (Mental Health 2002, 2012), Nutrition (2004, 2015), Healthy Aging (2010)	Cross-sectional	The CCHS is a general health survey that is limited in its ability to identify children and youth with neurodisabilities due to the age range of the sample and potential definitions of neurodisability.	The CCHS annual covers the population 12 years of age and over living in the ten provinces and the three territories. Excluded from coverage are: persons living on reserves and other Aboriginal settlements in the provinces, full-time members of the Canadian Forces, the institutionalized population, and persons living in some Quebec health regions.	Annual: 12+, Mental Health: 15+, Nutrition: 1+, Healthy Aging: 45+	The CCHS uses three sampling frames to select the sample of households: an area frame based on the LFS, a list frame of telephone numbers, and a Random Digit Dialling (RDD) frame. In the Nord-du-Québec and Prairie North health regions, only the RDD frame is used. In Nunavut, only the area frame is used. In the Yukon and Northwest Territories, most of the sample comes from the area frame but a small RDD sample is also selected in the territorial capitals.	Depends on the cycle; e.g., 2014 CCHS - Annual Component collected: Chronic conditions (heart disease, effects of stroke, high blood pressure, diabetes, and mood disorder) Health Utility Index (Optional content, some provinces only) Restriction of activities	Immigrant ^a Aboriginal ^a	General Canadian Population

Disability-Specific Surveys										
Health and Activity Limitations Survey (HALS)	Replaced by PALS	1986, 1991	Cross-sectional	The HALS is an early disability-specific survey which was replaced by PALS and then CSD. Children and youth with neurodisabilities can be identified based on several definitions.	The target population consisted of all persons with a physical or psychological disability who were living in Canada at the time of the Census, including residents of the Yukon and the Northwest Territories, and permanent residents of most collective dwellings and health care institutions. Indian reserves were covered by the APS. Persons excluded were residents in penal institutions, correctional facilities, military camps, campgrounds and parks, soup kitchens, merchant and coast guard ships and children's group homes.	All ages	The sampling frame was first based on positive responses to the activity limitation question on the Census. Results of field tests indicated that many persons with a disability did not answer "yes" to the question on activity limitation. Consequently it was decided to select a sample of individuals who responded "no" to the activity limitation, who were then interviewed. Some of these people changed their "No" to a "Yes" and were added to the sample of persons with disabilities.	1991 HALS - Household Component collected: Types of disabilities based on difficulty in hearing, seeing, speaking, mobility, agility and "other" domains. Other included intellectual disability, learning disability, and mental health in ages 15+ Chronic conditions (e.g., epilepsy, cerebral palsy (CP), spina bifida, learning disability for ages 0-14 only) Activity limitation(s) (single question for ages 0-14; limited in activity at home, at school, at work, in other activities for ages 15+) Main condition (ICD-9 codes are derived from the main conditions)	Immigrant ^a Aboriginal ^a	All persons with a physical or psychological disability living in Canada. Persons without disabilities on selected Census variables.
Participation and Activity Limitations Survey (PALS)	Replaced by CSD	Quinquennial, 2001, 2006	Cross-sectional	The PALS is a disability-specific survey which was replaced by CSD. Children and youth with neurodisabilities can be identified based on several definitions.	The population covered by the survey was persons living in private and some collective households in the ten provinces and the three territories. Exclusions include: the population living on First Nations reserves, residents of institutional collectives, individuals living on military bases, Canadian Armed Forces vessels, merchant vessels and coast guard vessels, as well as campgrounds and parks were excluded for operational reasons.	2006: Less than 15, 15-24, 25-44, 45-64, 65-74, 75+ 2001: Less than 25, 25-44, 45-64, 65+	The sampling frame consisted of all persons who answered "yes" to either of the Census questions on activities of daily living and who were living in Canada at the time of the Census.	2006 PALS collected: Types of disabilities based on difficulty in hearing, seeing, communication, mobility, agility, learning, developmental, and emotional/psychological domains. Chronic conditions (epilepsy, autism, CP, spina bifida, cystic fibrosis, fetal alcohol syndrome, attention deficit disorder/attention deficit and hyperactivity disorder (ADD/ADHD), Down syndrome, and complex medical care needs) Activity limitations Main condition (ICD-10 codes are derived from the main conditions) Health Utility Index	Immigrant ^a Aboriginal ^a	All persons with a limitation in daily living living in Canada. Persons without disabilities on selected Census variables.

Canadian Survey on Disability (CSD)	Active	Quinquennial, 2012	Cross-sectional	The CSD is a disability-specific survey, which does not include children. Youth (but not children under age 15) with neurodisabilities can be identified based on several definitions.	The population includes all adults aged 15 and over who had an activity limitation or a participation restriction associated with a physical or mental condition or health problem and were living in Canada at the time of the National Household Survey (NHS). This includes persons living in private dwellings in the ten provinces and three territories. The population living on First Nations reserves is excluded, as are people living in collective dwellings.	15-24, 25-44, 45-64, 65-74, 75+	The sampling frame includes all persons aged 15+ who answered "Yes" to at least one of the NHS filter questions on activity limitations and who lived in Canada at the time of the survey.	<p>Disability Screening Questions (DSQ)</p> <p>Types of disabilities based on the DSQ: seeing, hearing, mobility, flexibility, dexterity, pain, learning, developmental, mental/psychological, and memory</p> <p>Activity limitations (difficulty with activities of daily living obtained from the respondents' answers to the 2011 NHS)</p> <p>Main condition (ICD-10 codes are derived from the main conditions)</p>	Immigrant ^a Aboriginal ^b	<p>Canadians with an activity limitation or a participation restriction associated with a physical or mental condition or health problem.</p> <p>Persons without disabilities on selected NHS variables.</p>
Survey on Living with Neurological Conditions in Canada (SLNCC)	Inactive	2011	Cross-sectional	The SLNCC is a condition-specific follow up survey (to the CCHS) that is limited in its coverage due to the age range of the sample. Youth (but not children under age 15) with neurodisabilities can be identified based on several definitions.	The SLNCC covers the population 15 years of age and over living in the ten provinces who have been diagnosed by a health professional with one or more of the neurological conditions. Excluded from the survey coverage are: persons living on reserves and other Aboriginal settlements, full-time members of the Canadian Forces, the institutionalized population, and persons living in some Quebec health regions.	15+	The sample was drawn from CCHS respondents and household members aged 15+ (living in the ten provinces) who reported being diagnosed with at least one of the 18 neurological conditions of interest.	<p>Diagnoses (18 diagnoses; e.g., epilepsy, CP, spina bifida)</p> <p>Chronic conditions (heart disease, high blood pressure, diabetes, and mood disorder)</p> <p>Health Utility Index</p> <p>Restriction of activities (limitations in usual activities)</p>	Aboriginal - no Immigrant - no	N/A

Child and Youth Surveys										
National Longitudinal Survey of Children and Youth (NLSCY)	Inactive	Biennial, 1994-5...2008-09 (8 cycles)	Longitudinal	The NLSCY is a general child and youth survey with a focus on health. Children and youth with neurodisabilities can be identified based on several definitions.	The population includes the non-institutionalized civilian population (aged 0 to 11) in Canada's ten provinces. The survey excludes children living on Indian reserves or Crown lands, residents of institutions, full-time members of the Canadian Armed Forces, and residents of some remote regions.	Cycle 1: 0-11 Cycle 2: 0-13 Cycle 3: 0-15 Cycle 4: 0-17 Cycle 5: 0-5, 8-19 Cycle 6: 0-5, 10-21 Cycle 7: 0-9, 12-23 Cycle 8: 0-7, 14-25	All NLSCY samples were drawn from the LFS's respondent households.	<p><u>Cycle 1 (0-11 yrs):</u> Chronic conditions (e.g., epilepsy, CP, mental handicap/intellectual disability, learning disability, emotional/psychological/nervous difficulties); Activity limitations (limited in participation in school, at play, or in any other activity); Health Utilities Index (4-11 yrs only)</p> <p><u>Cycle 2 (0-13 yrs):</u> Chronic conditions (as above); Activity limitations; Health Utility Index (4-5 yrs)</p> <p><u>Cycle 3 (0-15 yrs):</u> Chronic conditions (as above); Activity limitations; Health Utility Index (4-5 yrs)</p> <p><u>Cycle 4 (0-15 yrs):</u> Chronic conditions (epilepsy, CP, mental handicap/intellectual disability); (learning disability, ADD, emotional/psychological/nervous difficulties; 3-15 yrs); Activity limitations; Health Utility Index (4-5 yrs)</p> <p><u>Cycle 5 (0-5; 8-19 yrs):</u> Chronic conditions (epilepsy, CP, mental handicap/intellectual disability); (learning disability, ADD/ADHD, emotional/psychological/nervous difficulties; 3-5, 8-19 yrs); Activity limitations; Health Utility Index (4-5 yrs)</p> <p><u>Cycle 6 (0-5; 10-21 yrs):</u>Chronic conditions (epilepsy, CP, mental handicap/intellectual disability); (learning disability, ADD/ADHD, emotional/psychological/nervous difficulties; 3-5, 10-21 yrs); Activity limitations (0-5; 10-19 yrs); Health Utility Index (4-5 yrs)</p> <p><u>Cycle 7 (0-9; 12-15; 18-19; 22-23 yrs):</u> Chronic conditions (epilepsy, CP, mental handicap/ intellectual disability); (learning disability, ADD/ADHD, emotional/psychological/nervous difficulties, eating disorder (3-9, 12-15, 18-19, 22-23 yrs); Activity limitations (0-9; 12-17; 20-21 yrs); Health Utility Index (4-5 yrs)</p> <p><u>Cycle 8 (0-7; 14-15; 18-19; 22-23 yrs):</u> Chronic conditions (epilepsy, CP, mental handicap/ intellectual disability); (learning disability, ADD/ADHD, emotional/psychological/nervous difficulties, eating disorder (3-7; 14-15; 18-19; 22-25 yrs); (autism, migraines; 3-7; 14-15); Activity limitations (0-7; 14-17; 20-21; 24-25 yrs); Health Utility Index (4-5 yrs)</p>	Immigrant* Aboriginal*	General Canadian Population

Aboriginal Children's Survey (ACS)	Inactive	2006	Cross-sectional	The ACS is an Aboriginal-specific child survey that is limited in its ability to identify neurodisability. A selected group of young Aboriginal children with neurodisabilities can be identified.	The target population includes all children in Canada with North American Indian, Métis or Inuit identity or ancestry, under the age of 6 years, excluding children living in Indian settlements or on-reserve, or in institutions. Although children living on-reserve were not included in the provinces, all Aboriginal children living in the territories and children in some First Nations communities in Quebec were included.	Under 6	The sample was selected from children living in households whose response on their 2006 Census questionnaire indicated that they had Aboriginal ancestors; and/or identified as North American Indian, Métis and/or Inuit; and/or had treaty or Registered Indian status; and/or had Indian Band membership.	Chronic conditions (CP, spina bifida, Down Syndrome, ADD/ADHD, Fetal alcohol spectrum disorder (FASD), autism) Activity limitation (single question)	N/A	N/A
Survey of Young Canadians (SYC)	Inactive	2010	Cross-sectional	The SYC is a general child survey with some health content but is limited in the age range included in the sample. A selected group of children (but not children aged 10 or older) with neurodisabilities can be identified.	The target population consists of Canadian children 1 to 9 years of age living in the ten provinces, excluding those living on an Indian reserve or in an institution.	1-5, 6-9	Respondents were randomly selected from administrative files produced by Statistics Canada using information obtained from the Canada Revenue Agency.	Chronic conditions (e.g., epilepsy, CP, learning disability, autism, emotional/psychological/ nervous difficulty) Restriction of activities	Immigrant ^a Aboriginal ^a	General Canadian Population
Ontario Child Health Study (OCHS)	Active	Occasional	Cross-sectional	The OCHS is a survey of children and youth living in Ontario only. Children and youth with neurodisabilities can be identified based on several definitions.	Children and youth aged 4 to 17 living in Ontario. Excluded from the sample are children living on reserves and those living in institutions.	4-11, 12-13, 14-17	The dwellings for this survey come from administrative files created by Statistics Canada and Canada Revenue Agency (the Canadian Child Tax Benefit file).	Developmental conditions (developmental delay, intellectual disability, autism spectrum disorder, ADD/ADHD, learning disability) Chronic health conditions (epilepsy, CP) Health Utility Index	Immigrant ^a Aboriginal ^a	General Ontario Population
Other Surveys										
General Social Survey (GSS)	Active	Annual, topic varies (quinquennial, same topic)	Cross-sectional	The GSS is a general population survey that is limited in its ability to identify children and youth with neurodisabilities due to the age range of the sample and potential definitions of neurodisabilities.	The target population is all non-institutionalized persons 15 years of age and over, living in the ten provinces.	15+	Depends on the topic. e.g. GSS -Victimization (2014 Cycle 28: Canadians' Safety) is based on Statistics Canada's new telephone sampling frame.	Depends on the cycle; e.g., GSS -Victimization (2014 Cycle 28: Canadians' Safety) DSQ (short version)	Immigrant ^a Aboriginal ^a	General Canadian Population

Longitudinal and International Study of Adults (LISA)	Active	Biennial, 2012	Longitudinal but only wave 1 currently available (2012)	The LISA is a general survey of adolescents and adults, which is limited in its ability to identify children and youth with neurodisabilities due to the age range of the sample and potential definitions of neurodisabilities.	The LISA covers the population living in the ten provinces, plus their future descendants. Excluded from the survey's coverage are those who were: living on reserves and other Aboriginal settlements in the provinces, official representatives of foreign countries living in Canada and their families, members of religious and other communal colonies, members of the Canadian Armed Forces stationed outside of Canada, and persons living in institutions.	15-65	The sample is selected from a frame constructed from dwellings containing households which responded to the 2011 Census of Population.	<p>Any longstanding illness that has lasted or expected to last 6 months or more (single question in Wave 1)</p> <p>Activity limitation due to longstanding illnesses (single question in Wave 1)</p> <p>DSQ (long version in Wave 2; short version in Wave 3)</p>	Immigrant ^a Aboriginal ^a	General Canadian Population
Aboriginal Peoples Survey (APS)	Active	1991, 2001, 2006, 2012	Cross-sectional	The APS is an Aboriginal-specific survey that is limited in its ability to identify children and youth with neurodisabilities due to potential definitions of neurodisabilities.	The target population was composed of the Aboriginal identity population of Canada, 6 years of age and older, living in private dwellings excluding people living on Indian reserves and settlements and in certain First Nations communities in Yukon and the Northwest Territories.	6+	The sample was selected from NHS respondents who reported an Aboriginal identity or ancestry.	Chronic conditions (for 0-11 years: learning disability, autism, fetal alcohol syndrome, developmental disability, ADD/ADHD; for 12+ years: mood or anxiety disorders, ADD, learning disability)	N/A	N/A

^a Although an indicator is included on the data file, caution is warranted as the sample size might not be sufficient for specific analysis.

ICD = International Classification of Diseases.

TABLE 2 SOCIAL DETERMINANTS VARIABLES OF INTEREST

Data source	Utilization of health and social services*	Health utility measures*	Income*	Marital Status*	Education*	Employment*	Ethnocultural background	Personal health practices and coping skills	Social environment	Social support
General Health Surveys										
National Population Health Survey (NPHS)	Doctors' visits Hospitalization Medication use	Health Utility Index (HUI)	Self-reported household and personal income, general sources of income	Self-reported current marital status	Highest educational attainment	Self-reported labour force participation	Ethnocultural status Immigration status Aboriginal status	Coping with stress (only in certain cycles)	N/A	Social support module (Medical Outcomes Study questions)
Canadian Community Health Survey (CCHS)	Doctors' visits Hospitalization Medication use	HUI Short Form (36) Health Survey (SF-36) optional content in some cycles (e.g., 2013, 2014 Yukon T)	Self-reported household and personal income, general sources of income	Self-reported current marital status	Highest educational attainment	Self-reported labour force participation	Ethnocultural status Immigration status Aboriginal status	Coping with stress (optional content, certain respondents in certain cycles only)	Social Provisions Scale (optional content, some cycles only) Neighbourhood environment (optional content, some cycles only)	Social support module (optional content, some cycles only)
Disability-Specific Surveys										
Health and Activity Limitations Survey (HALS)	Doctors' visits Hospitalization Medication use	N/A	Self-reported household income, general sources of income, low income status, other selected income variables from Census	Self-reported marital status (reported and historical)	Highest educational attainment	Self-reported labour force participation (adult version)	Ethnocultural status Immigration status Aboriginal status	N/A	N/A	N/A
Participation and Activity Limitations Survey (PALS)	Doctors' visits Medication use	HUI	Self-reported household income, general sources of income, low income status, other selected income variables from Census	Self-reported marital status (legal and historical)	Highest educational attainment	Self-reported labour force participation	Ethnocultural status Immigration status Aboriginal status	Impact on parents module	N/A	Social support
Canadian Survey on Disability (CSD)	Medication use	N/A	Self-reported household income, general sources of income, low income status, other selected income variables from NHS	Self-reported marital status (legal and de facto)	Highest educational attainment	Self-reported labour force participation	N/A	N/A	N/A	N/A
Survey on Living with Neurological Conditions in Canada (SLNCC)	Medication use	HUI	Self-reported household income	Self-reported marital status	Highest educational attainment	Self-reported labour force participation	N/A	N/A	N/A	Social support

Child and Youth Surveys										
National Longitudinal Survey of Children and Youth (NLSCY)	Doctors' visits Medication use Hospitalization	HUI	Self-reported household and personal income, ratio to low income cutoff (C1-C5), income adequacy (C1-C5), general sources of income	Child living arrangements, PMK current marital status	Highest educational attainment (self and parent)	PMK and spouse labour force participation	Ethnocultural status Immigration status Aboriginal status	PMK and spouse health	Neighbourhood safety Family functioning	Social support
Aboriginal Children's Survey (ACS)	Doctors' visits Medication use	N/A	Self-reported household income	Child living arrangements	Highest educational attainment (PMK and spouse)	PMK and spouse labour force participation	N/A	PMK self-rated health	Single question on housing satisfaction	Single question on satisfaction with support network.
Survey of Young Canadians (SYC)	Doctors' visits Medication use	N/A	Self-reported household and personal income	PMK current marital status	Highest educational attainment (PMK and spouse)	PMK and spouse labour force participation	Ethnocultural status Immigration status Aboriginal status	PMK and spouse health	Neighbourhood safety	Social support
Ontario Child Health Study (OCHS)	Doctors' visits Medication use Hospitalization/ Emergency room visit	HUI	Self-reported household income and general sources of income (request to link to tax data)	PMK current marital status	Highest educational attainment (PMK)	PMK labour force participation	Ethnocultural status Immigration status Aboriginal status	PMK and spouse functional limitations PMK mental health	Neighbourhood characteristics, safety Family functioning	N/A
Other Surveys										
General Social Survey (GSS)	N/A	N/A	Self-reported household income and general sources of income	Self-reported current and previous marital/common law status	Highest educational attainment (self and parent in some cycles)	Self-reported labour force participation	Ethnocultural status Immigration status Aboriginal status	N/A	Neighbourhood environment (some cycles)	N/A
Longitudinal and International Study of Adults (LISA)	N/A	N/A	Linked from administrative (tax) data	Self-reported current marital status	Highest educational attainment (self and parent)	Self-reported labour force participation	Ethnocultural status Immigration status Aboriginal status	N/A	N/A	N/A
Aboriginal Peoples Survey (APS)	N/A	N/A	Self-reported household and personal income, general sources of income	Self-reported legal marital status, common law status	Highest educational attainment	Self-reported labour force participation	N/A	N/A	Housing	Community support

Note: For surveys collected in multiple years, variables collected may not be exactly the same for all cycles. Some caution is warranted and each variable of interest should be examined separately for sample size and representativeness of the data.

NOTE: PMK is the Person Most Knowledgeable about the child.

* variable that can be used in economic evaluation methodology.

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