

Global Report on Developmental Delays, Disorders and Disabilities

Canada

April 2021



Acknowledgements

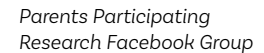
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“Lack of support. Zero respite. Zero. That’s how it is for every parent of a disabled child. For those who are single parents, their emotional & mental health is deteriorating. There is zero help. Zero.”

BACKGROUND & OBJECTIVES

The Global Report on Developmental Delays, Disorders and Disabilities was convened by the World Health Organization, UNICEF, and Autism Speaks to document the experiences of caregivers of children, youth, and adults with these conditions around the world. The aims of the Global Report include increasing awareness, compiling data, providing guidance on strengthening health systems, and engaging international and country-level partners.

Activities of the Global Report began prior to the COVID-19 pandemic and acquired new significance as people with delays, disorders and disabilities, and their supportive communities were confronted by additional challenges.

The objectives of the Global Report in Canada were:

1. To assess the impact of the COVID-19 pandemic on the health and wellbeing of caregivers and their children.
2. To understand the patterns of help seeking access to services and supports prior and during the pandemic.

METHODS

A Global Report Caregiver survey was developed, tested, and disseminated in collaboration with caregivers of children with these conditions in Canada. Survey questions were based on COVID-19 UNICEF and WHO policy guidance recommendations for persons with disabilities and included topics such as response to the pandemic, access to care and supports, mental health impact, and coping.

This survey was distributed online through numerous social media platforms and mail lists of partner organizations. Data were collected from June to July 2020 from a non-random sample of self-identified caregivers of children, youth, and adults with disabilities from across Canada.

A consultation was convened to share key findings with a group of policy- and decision-makers in September 2020. Discussions in this consultation focused on putting the survey data in context, planning results dissemination, and the use of the findings to support the ongoing policy response for COVID-19.

This report presents descriptive findings of the survey data including caregivers’ perceptions of mental health, coping, and well-being of themselves and their children before and during the COVID-19 pandemic.

KEY FINDINGS

A total of 883 caregivers of children and youth with disabilities (age 0-41 years) completed the survey.

Direct Health Impacts of COVID-19

Over one third (35%) of caregivers reported that they or someone in their home had gotten tested for COVID-19. About 6% reported that they or someone in their home had COVID-19.

Coping and Health

Over half of caregivers found it difficult to cope (e.g., keep a healthy lifestyle) or help the child with the disability cope (e.g., keep child's normal routine) during the pandemic. The majority of caregivers were worried about their health and the health of the child with the disability. Changes in their child's functioning were reported: sleep problems, mental health problems, and repetitive behaviours had worsened. Yet, a small group noticed some improvement in their child's functioning during the pandemic.

“
It was difficult to maintain social distancing within my household and it was difficult to stop my child from touching everything when going out in public as he did not understand.
”

Access to Services, Information, and Supports

Accessing services and supports was challenging. Difficulties faced included:

1. Maintaining their formal and informal support networks
2. Receiving enough telehealth services for themselves and regular or telehealth services for their child.
3. Having financial or technical support to work from home
4. Getting schooling (daycare, pre-school, school) or educational plans for schooling their children at home
5. Figuring out available services/supports that were still available
6. Having COVID-19 information that was accessible for their children
7. Over a third of caregivers indicated it had been difficult to making enough money for essentials (over one third of caregivers reported it had been difficult to make enough money to get by)

When considering the period prior to the pandemic, caregivers reported challenges in:

1. Obtaining accurate information on how best to address the child's needs
2. Accessing services to manage and support the needs of their child
3. Accessing education for their child
4. Obtaining additional support for their child at school.

Part 1: Introduction

1.1 BACKGROUND & OBJECTIVES

The World Health Organization (WHO), in partnership with UNICEF and Autism Speaks, convened the Global Report on Developmental Delays, Disorders and Disabilities to document the lived experiences of caregivers of children with these conditions and thereby generate country-level data that can be used to inform advocacy, policy, and program planning efforts. The Global Report acquired new significance as the world faced new challenges resulting from the COVID-19 pandemic. Consequently, the Global Report will present a country-level “report card” on the status of developmental delays, disorders and disabilities as well as the impact of COVID-19 on these families.

In Canada, 6.2 million Canadians aged 15 years and over (22% of the population) reported having at least one disability and 315,470 (1%) reported having a developmental disability.¹

Canada has ratified human rights treaties, namely the United Nations Convention on the Rights of the Child (UNCRC) and the Convention on the Rights of Persons with Disabilities (UNCRPD), that underscore the rights of persons with disabilities to enjoy a full and decent life, optimal standard of care, and full participation in society. Nevertheless, Canadians with disabilities continue to face systemic inequalities such as unequal access to healthcare, social services, education, and limited participation in the community and play.

Following the declaration of the World Health Organization of the coronavirus outbreak (COVID-19) as a pandemic in March 2020, Canada, as most countries in the world, implemented public health measures to manage and prevent the spread of the virus. The impact of the pandemic and of the public health measures to contain the virus on families affected by neurodevelopmental disabilities was unknown.

Given the lack of disaggregated data on the impact of COVID-19 on Canadians with disabilities and their families, the Global Report was a timely opportunity to fill knowledge gaps in this area and inform ongoing policy response both in Canada and internationally.



¹Morris, S., Fawcett, G., Brisebois, L., & Hughes, J. (2017). A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017. Statistics Canada. Available from: <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018002-eng.pdf>

Part 2: Methods

2.1 SURVEY DEVELOPMENT

The survey was designed to: (1) assess the impact of the COVID-19 pandemic on the lives of parents and other primary caregivers of children or adults (of all ages) with a neurodevelopmental condition, and (2) contribute to the World Health Organization's Global Report on Developmental Delays, Disorders, and Disabilities by documenting caregivers' experiences before and during the pandemic. Survey questions were based on COVID-19 policy recommendations for persons with disabilities developed by the World Health Organization and UNICEF as well as CRPD (Convention on the Rights of Persons with Disabilities) article 11 illustrative indicators, on situations of risk and humanitarian emergencies.

The survey consisted of three main modules:

1. The first module focused on COVID-19 and included questions about direct and indirect impacts of the virus, measures taken to reduce potential exposure, barriers and facilitators to keeping safe, coping, continuity of care, and access to information, services, and supports during the pandemic.
2. The second module included demographic questions pertaining to caregivers as well as the child with the disability. Questions included their age, gender, geographic region of residence, relationship to the person with the disability, ethnicity, education, work and household status, income, status in Canada (e.g., Canadian by birth, refugee, etc.), and whether they had a disability themselves.

Caregivers were also asked about the child's diagnosis, age, gender, and the type of school the child attended.

3. The final module included questions about the child's developmental history and diagnosis, the caregivers' help-seeking behaviour prior to the pandemic, and the availability and ease of accessing services prior to the pandemic.

Ethics approval

The McGill University Faculty of Medicine Research Ethics Board approved the use of this survey for research purposes.

Pilot testing

Survey Monkey, an online survey platform, was used. The survey was pilot tested with 10 "parent-partners," representing parents of children with disabilities of different ages and diagnoses. Parent-partners were asked to provide feedback on: (1) content (e.g., whether areas covered were relevant, whether important areas were missed), (2) language (e.g., whether questions were easy to understand), (3) format (e.g., whether the flow of the questions was acceptable, whether there were technical glitches), and (4) any other aspect of the survey that required adjustments. The survey was then revised based on parent-partners' feedback. Originally developed in English, the survey was translated to French so it could be available in both official languages in Canada.

Compensation

Caregivers were offered \$15 in appreciation for their participation.

2.2 DATA COLLECTION

The survey was launched on June 11, 2020, three months after the World Health Organization declared the outbreak of COVID-19 as a pandemic and provinces across Canada began to take measures to manage the outbreak. The link to the survey remained active for over five weeks, officially closing July 21, 2020.

To participate, respondents had to be the primary caregiver of a child or adult (any age) with a disability. A non-random, convenience sample of caregivers from across provinces and territories in Canada was sought.

The research team approached researchers, organizations, research centres, and research networks in various provinces/territories via an information/invitation e-mail to inform them about the study and asked them to share this information through their e-mail distribution lists, newsletters, or research websites. Parent-partners were also asked to share study information and the link to the survey through their networks. Finally, study information and the link to the survey were also shared through social media platforms (e.g., Facebook and Twitter) by team members and parent-partners.

2.3 DATA VALIDATION

Upon survey closure, the dataset (n = 2,133) was verified for invalid responses. Strategies used to identify potentially invalid cases included checking for: (1) duplicate IP addresses, (2) incorrect responses in free text fields (e.g., respondent's name), (3) duplicate responses in open-ended questions, (4) duration of questionnaire completion (e.g., completing the survey in less than 10 minutes), (5) impossible time gap between respondent and child age, and (6) cases where the same answer (e.g., "b") was selected repeatedly.

The following criteria were then used to confirm cases as invalid: (1) inconsistency between name in consent, parental gender, and relationship to child (e.g., gives female name in consent and reports being biological father), (2) inconsistent responses to questions related to child age at diagnosis (e.g., age when concerns were first noticed, age at diagnosis), (3) a period or no space in the name provided for consent purposes, (4) an email address that started with the full name and was followed by numbers, (5) a date of birth in the consent date field, and (6) postal codes reported in U.S.A format.

All cases that matched the above mentioned screening criteria were deleted from the dataset, resulting in a total of 883 valid responses.

2.4 STAKEHOLDER CONSULTATION

On September 23, 2020, a group of 16 stakeholders representing government (federal, provincial, municipal), community organizations, and persons with disabilities (parents and youth) met through a virtual roundtable with the research team to discuss findings from the Global Report Caregiver survey.

The project background and preliminary results were shared with participants. Feedback was obtained on how the findings could support and inform the ongoing policy responses to the COVID-19 pandemic in Canada. Further, stakeholders offered a range of suggestions to inform more targeted analyses and dissemination mechanisms for survey results.

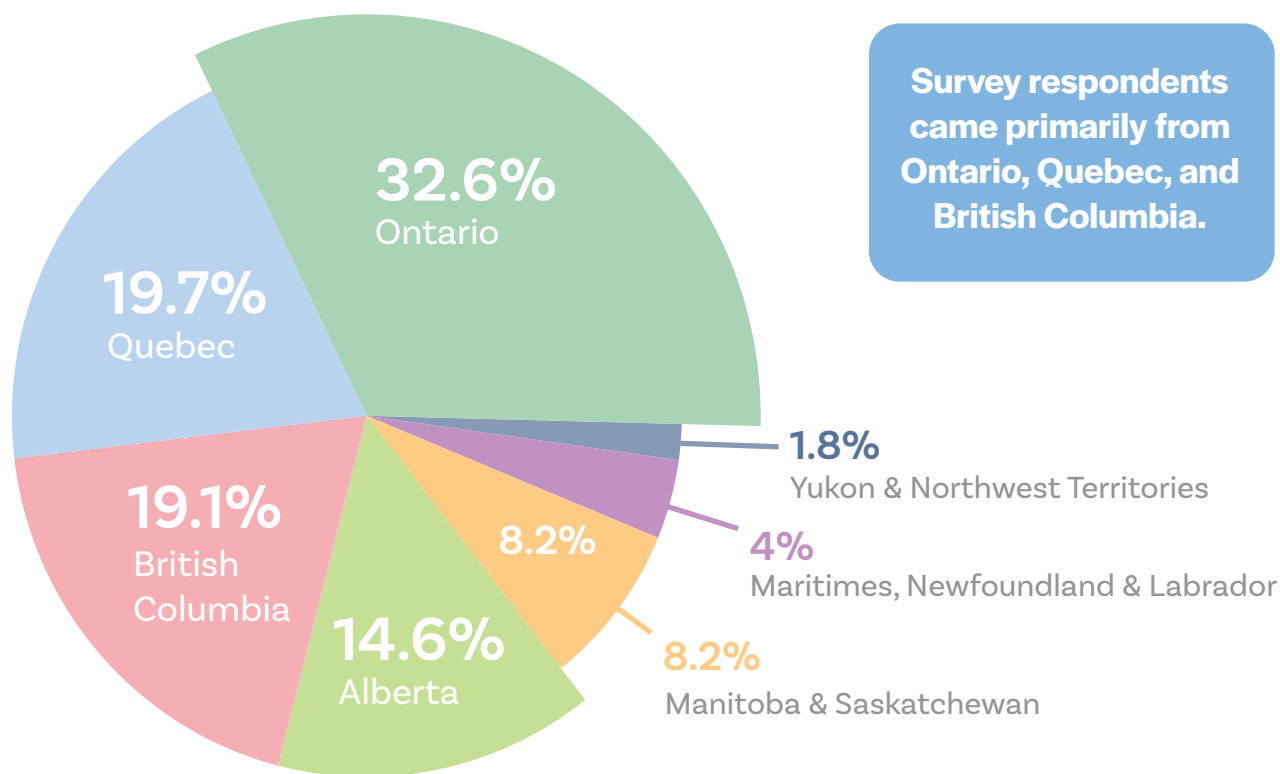
Findings reported here are based on descriptive statistics. Additional analyses are ongoing to address more specific research questions motivated by the consultation as well as the current state of knowledge in this area.

Part 3: Results

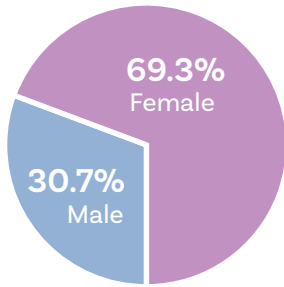
Results are based on the 883 valid survey responses retained for analysis (737 caregivers completed the survey in English, while 146 completed the survey in French).



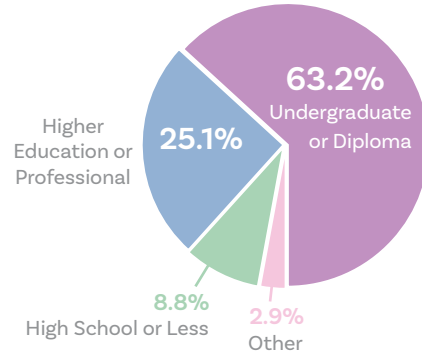
Respondents by Province



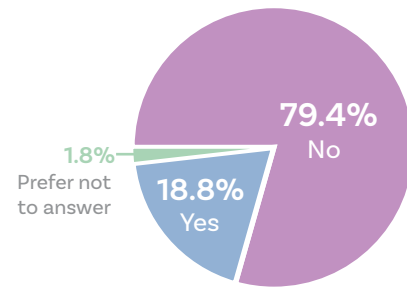
Gender



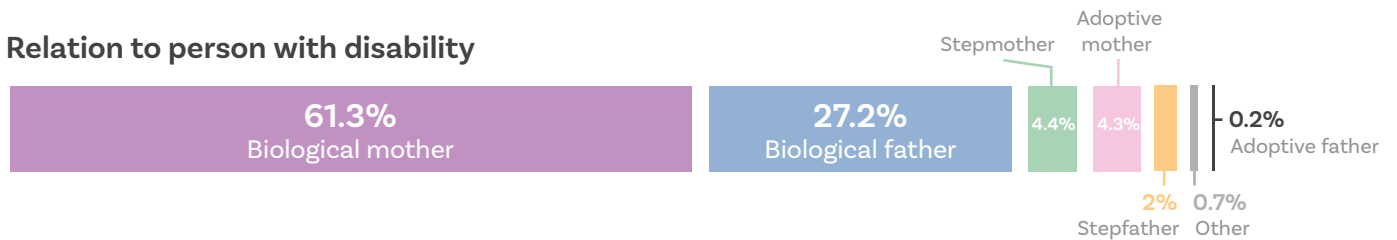
Education



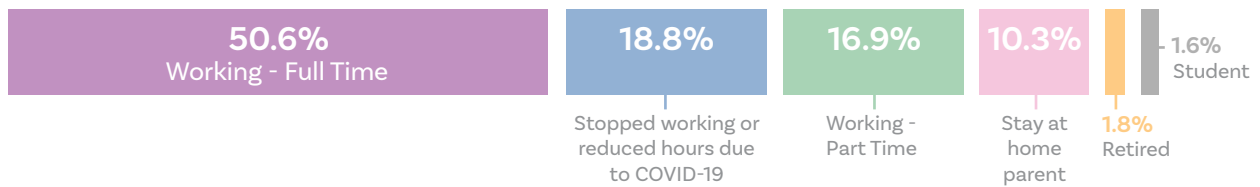
Disability



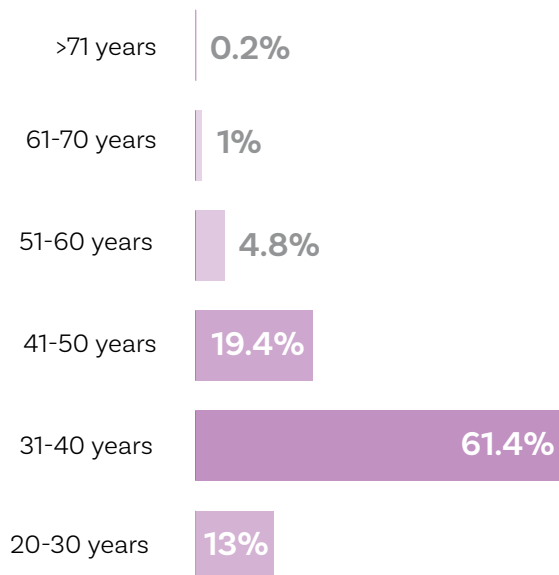
Relation to person with disability



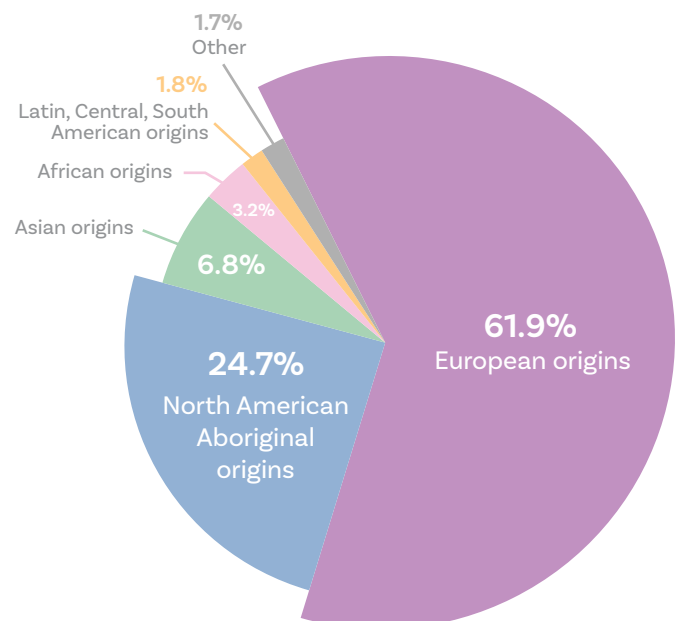
Work status



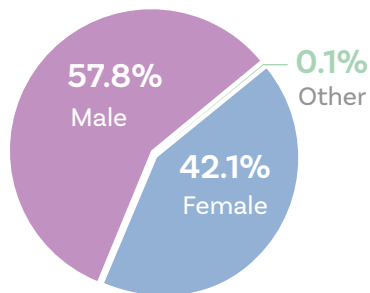
Age



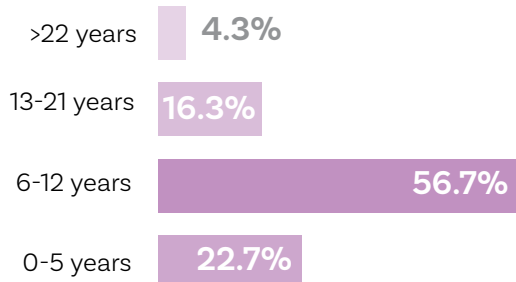
Ethnicity



Gender

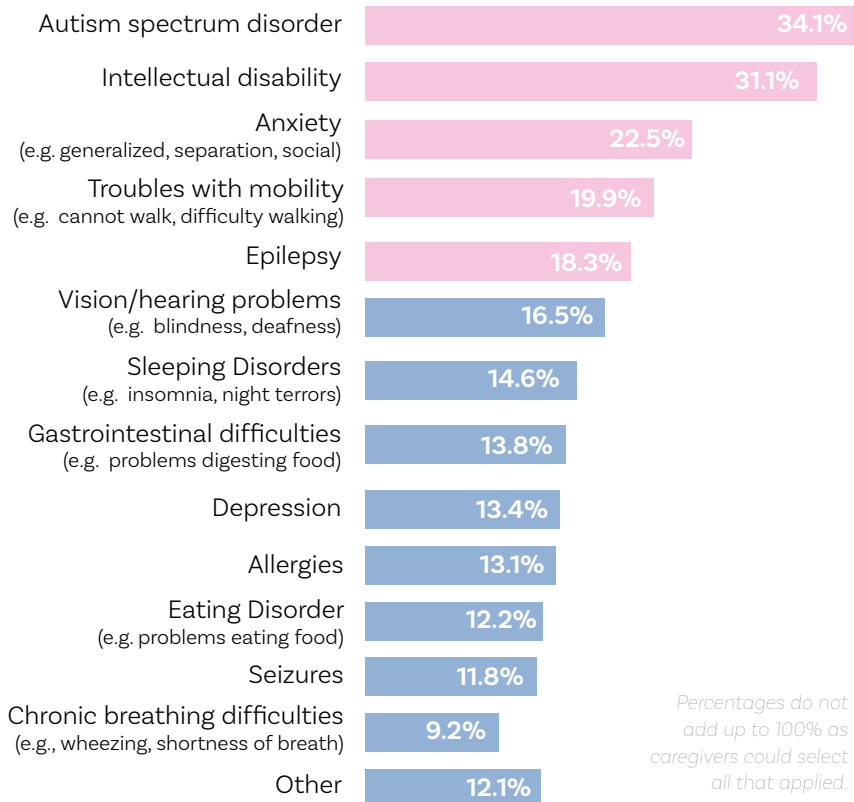


Age



The mean age for the child or adult with the disability was 9 years (age range of 0 to 41 years).

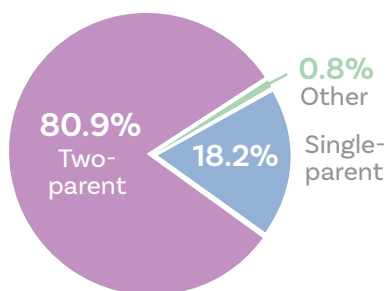
Conditions child has been diagnosed with



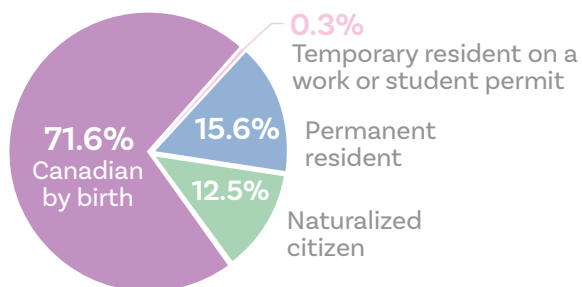
Percentages do not add up to 100% as caregivers could select all that applied.

HOUSEHOLD CHARACTERISTICS

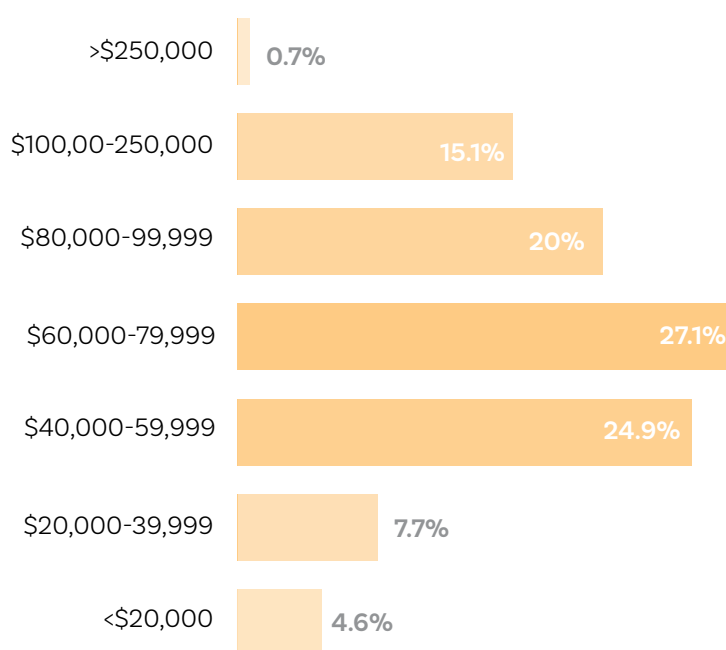
Household Status



Status in Canada



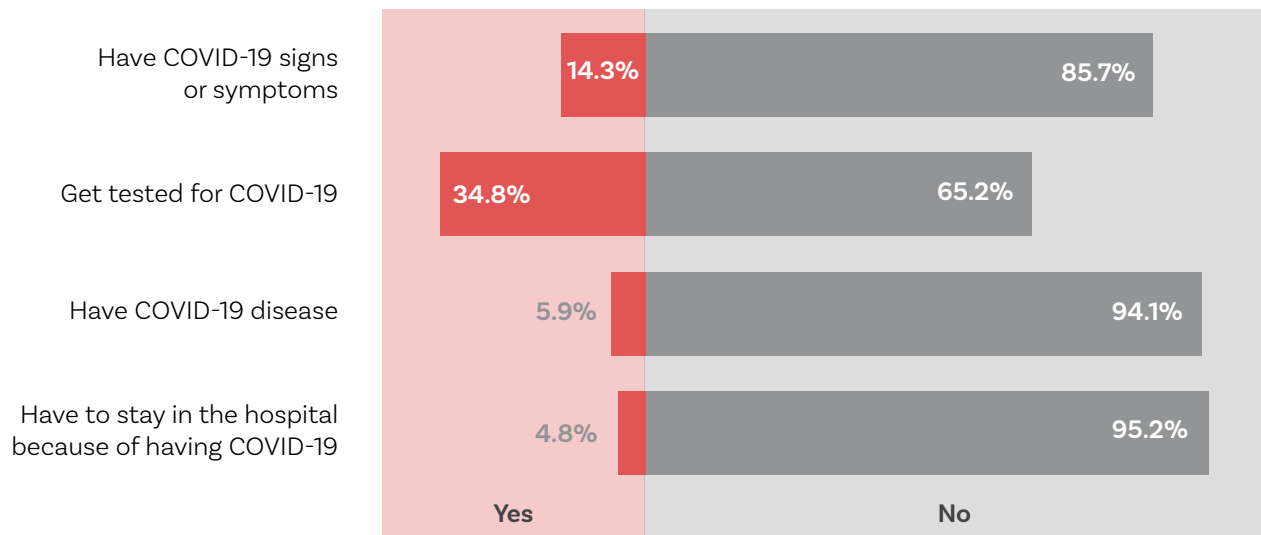
Household Income



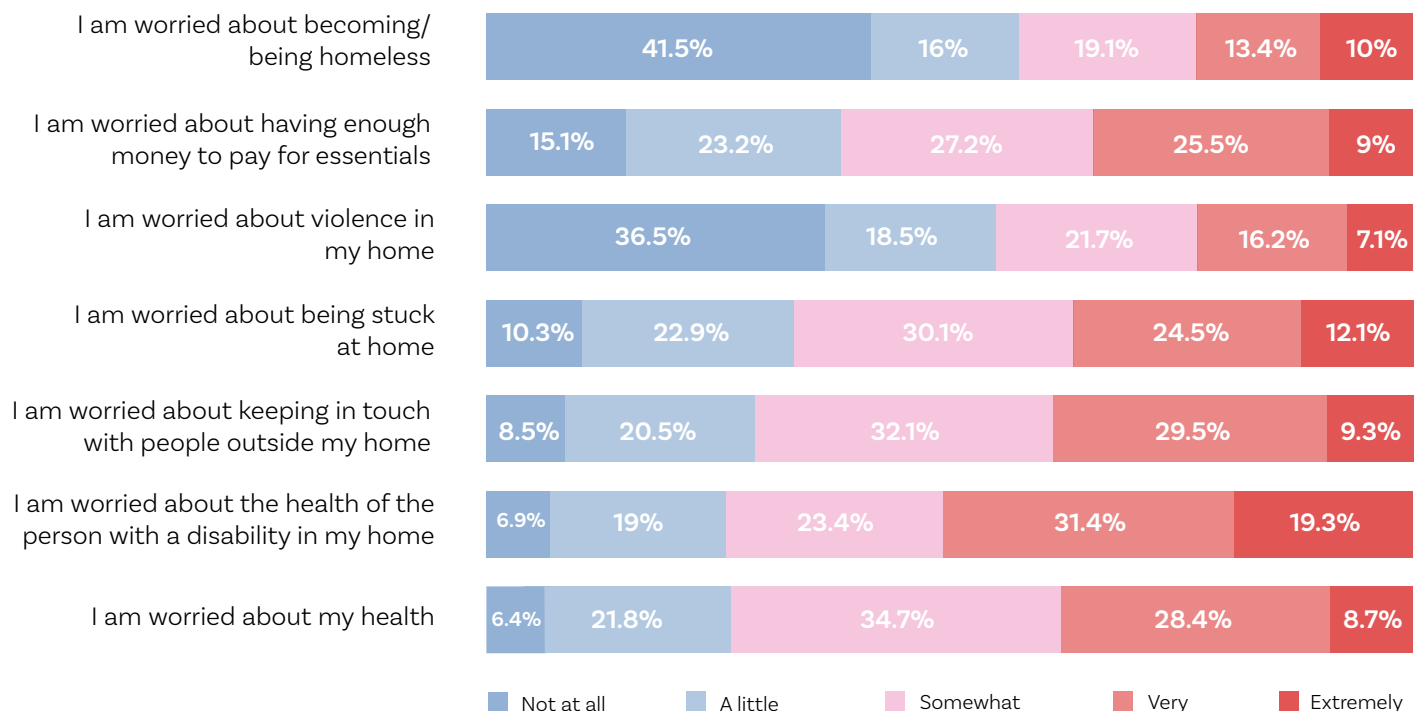
Worries during COVID-19

Over one-third of caregivers (34.8%) reported that they or anyone in the home got tested for COVID-19. While the majority of caregivers did not have any COVID-19 signs or symptoms, have COVID-19 disease, or had to be hospitalized from COVID-19, the pandemic has induced a variety of worries: almost all of the caregivers reported being somewhat, very or extremely worried during the pandemic. Chief among their concerns were worries about their health, the health of the child with disability, and having enough money for essentials. Over half of caregivers reported worries about violence in the home (63.5%) and becoming homeless (58.5%).

During the pandemic, did you or anyone in your home...



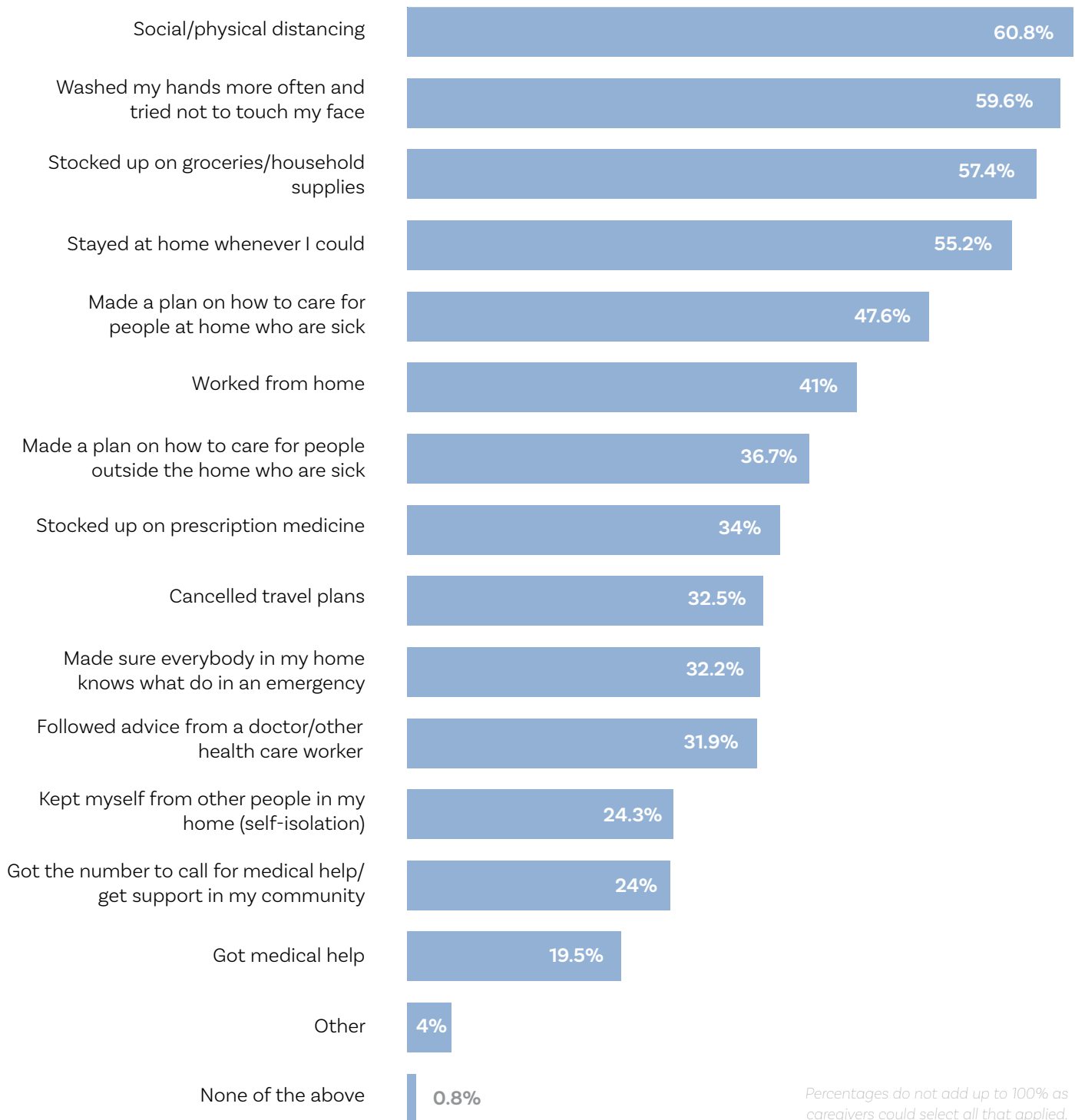
How worried were you about the following areas?



Staying safe

Among the most common strategies used to keep safe during the pandemic, were social and physical distancing, washing hands and trying not to touch the face, and stocking up on groceries and household supplies. The least endorsed strategies used to keep safe were getting medical help, getting a number to call for medical help or community support, and self-isolating at home.

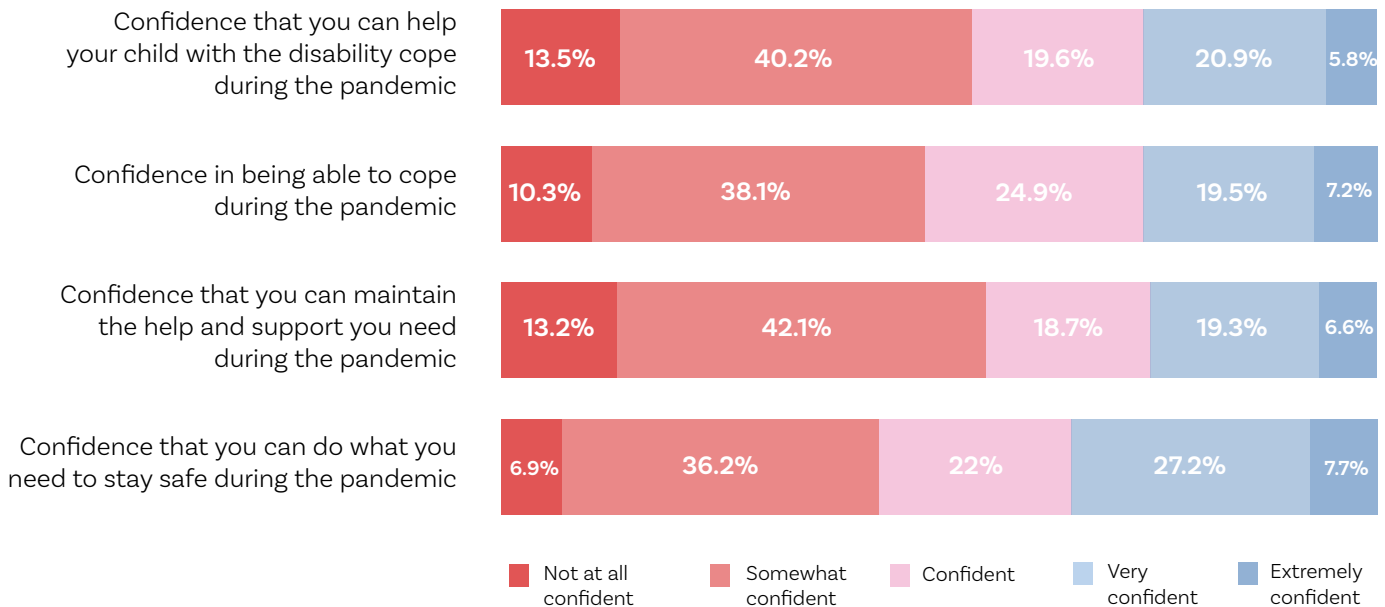
What have you done to keep safe?



Percentages do not add up to 100% as caregivers could select all that applied.

Caregiver confidence

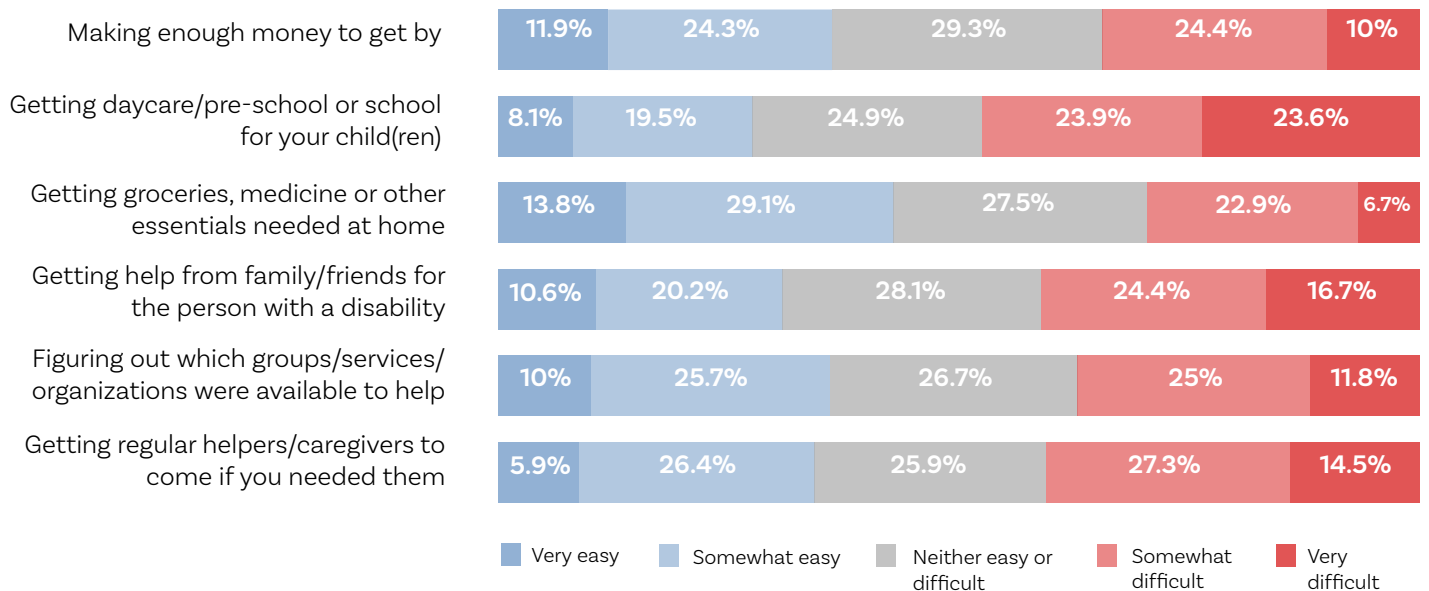
Over half of the caregivers felt somewhat confident or confident that they can cope during the pandemic, including that they can 1) help their child with the disability cope, 2) maintain the help and support they need, and 3) do what they need to stay safe during the pandemic.



Continuity of care and support

Caregivers reported difficulty in maintaining care and support during the pandemic. Almost half of the caregivers indicated that during the pandemic it was somewhat or very difficult to get schooling for their child or children, to get help from their family or community for the person with a disability in their home, and to get their regular helpers or caregivers to come if they needed them.

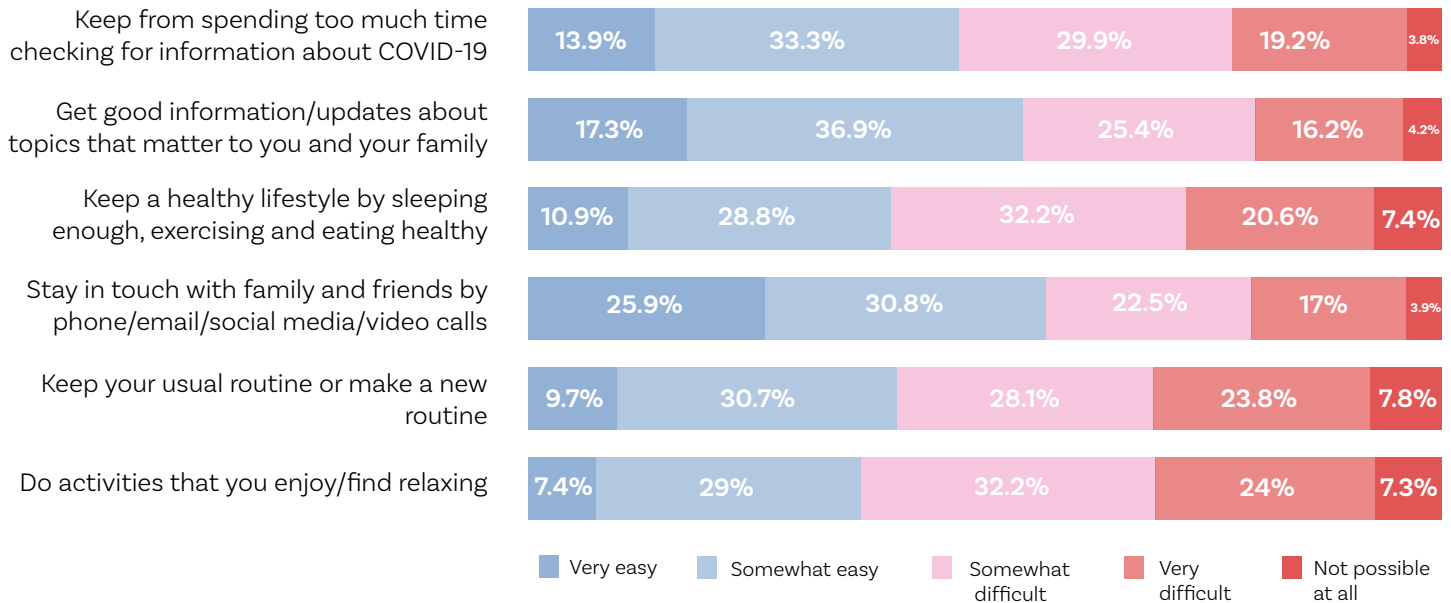
How easy has it been to maintain help and support for your family?



Coping as a caregiver

Over half of the caregivers also found it somewhat difficult or very difficult to keep a healthy lifestyle, maintain or make a new routine, or do activities they find enjoyable/relaxing. Despite these difficulties, over half of the caregivers were able to stay in touch with family and friends through the pandemic.

How easy was it to do the following for yourself?

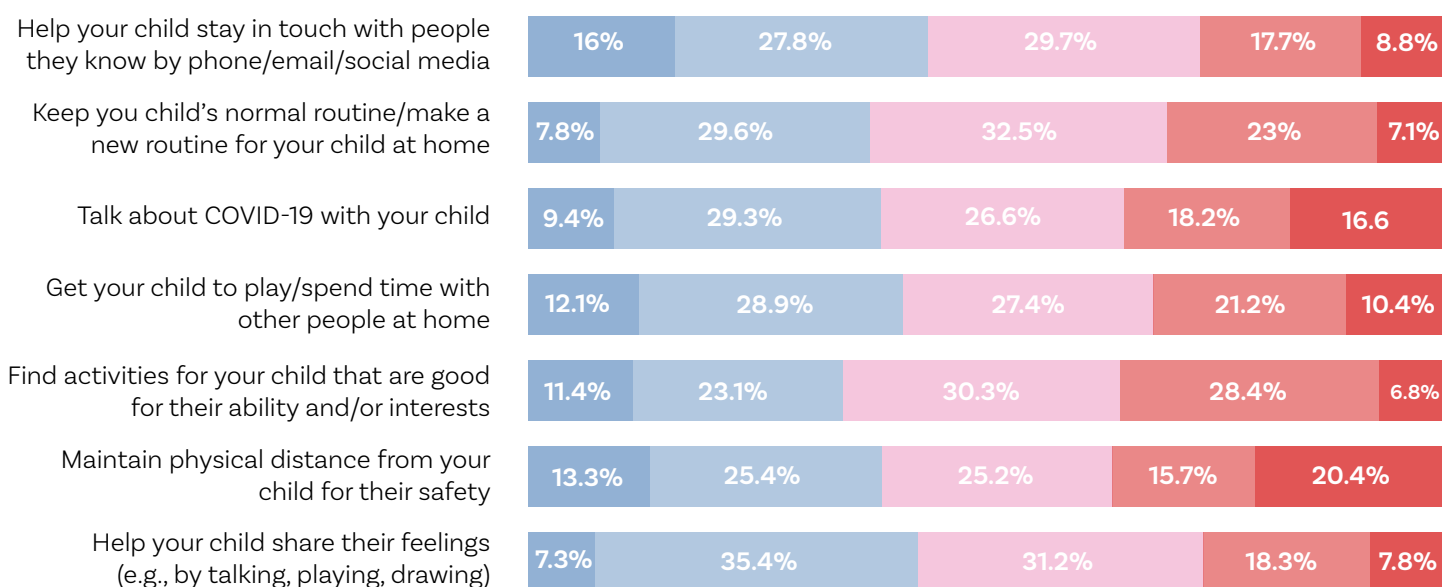


Note: The same scale is used below.

Helping the child with a disability to cope

Over half of the caregivers found it somewhat difficult or very difficult to find activities for their child that are good for their ability and/or interests. Helping their child share their feelings or getting their child to play or spend time with others in the home was also difficult for many parents (50-60%). Over half of the caregivers found it difficult to maintain physical distance from their child for their safety, with 20% of caregivers reporting it impossible to do so.

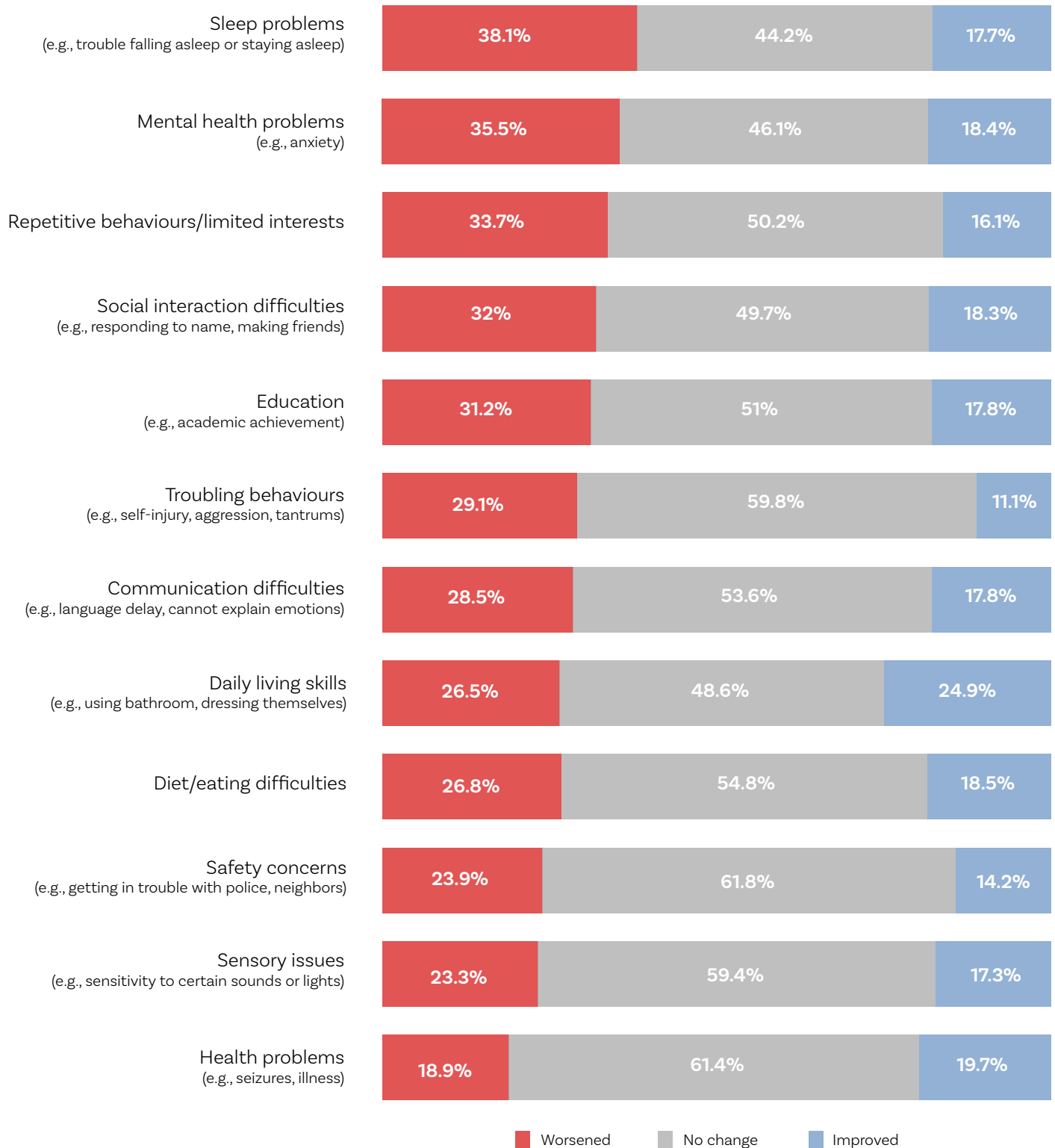
How easy was it to do the following for your child with a disability?



Changes in child functioning during the pandemic

Across 12 domains of functioning, sleep was most commonly reported to have worsened followed by mental health, repetitive behaviours/limited interests, and social interaction. One quarter of caregivers reported that daily living skills (e.g., using bathroom) had improved.

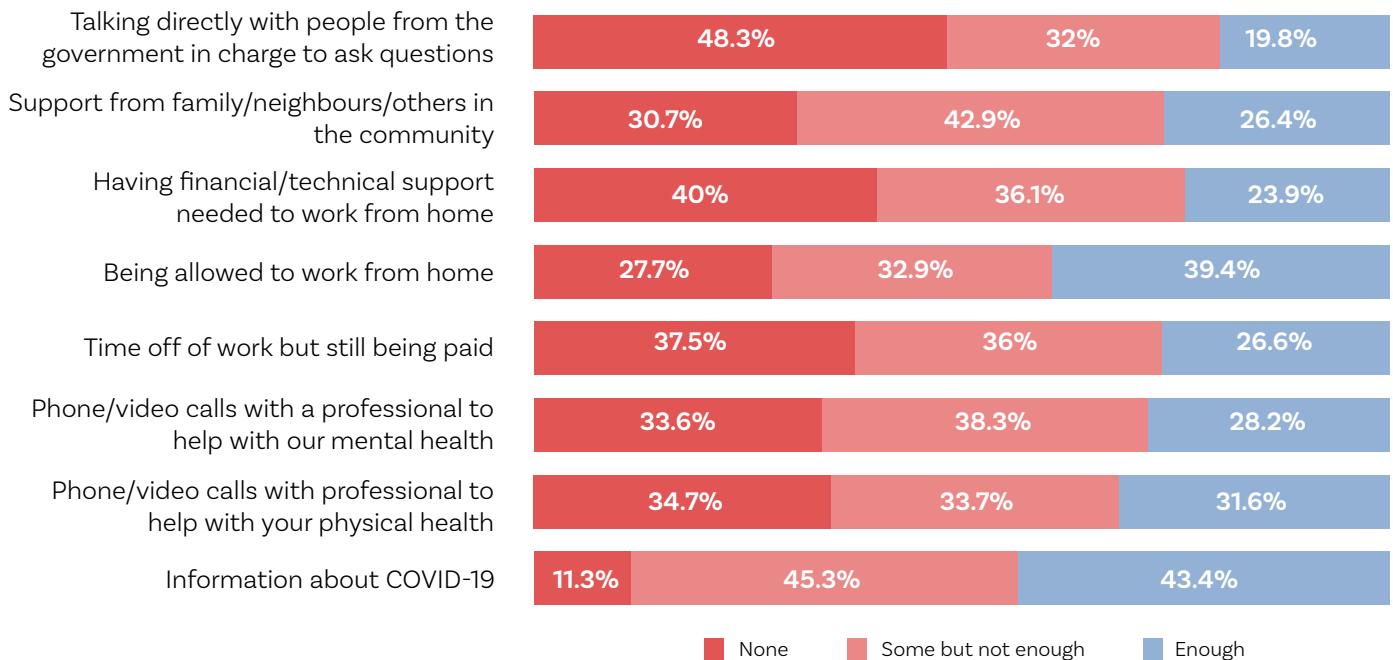
Changes in the child during the pandemic



Access to information, services and supports for the caregiver

Overall there were limitations in access to information, services, and support. Almost half of caregivers reported having “Some but not enough” information about COVID-19 (45.3%) or support from family and others in the community (42.9%). In terms of telehealth services for physical or mental health, over one third reported having “Some but not enough” telehealth services for their mental health (38.3%) or physical health (33.7%).

Have you gotten enough information, services, or support in the following areas:

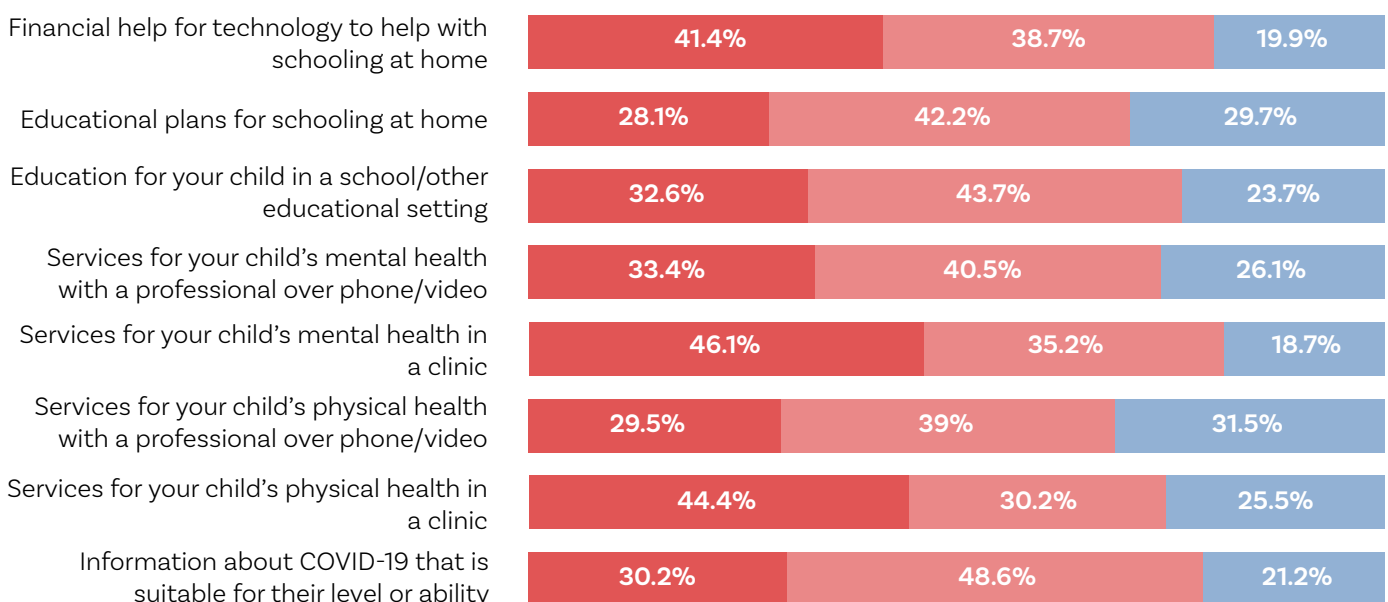


Note: The same scale is used below.

Access to information, services and supports for the child with a disability

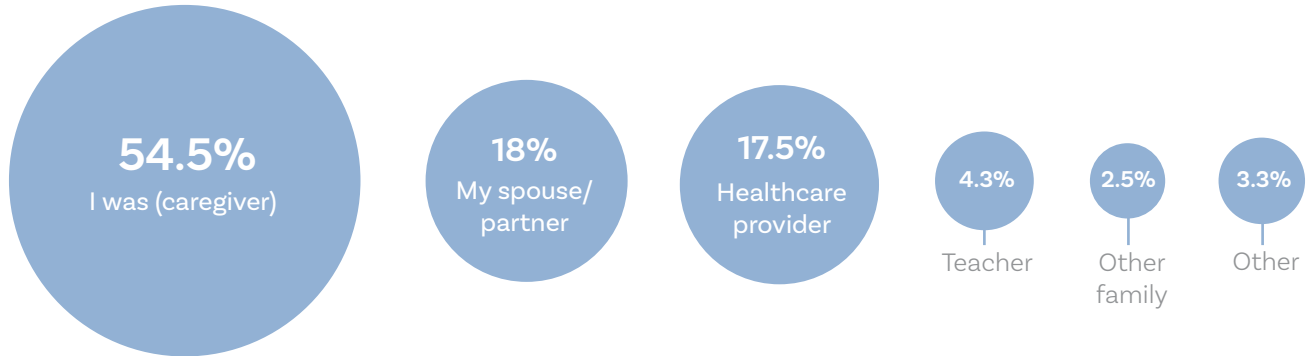
Almost half of caregivers (48.6%) reported having “Some but not enough” information about COVID-19 that was suitable for their child’s level or ability. In terms of telehealth services, less than one third reported having enough services for their child’s mental health (26.1%) or physical health (31.5%). Similarly, less than one third of caregivers reported having enough in-clinic services for their child’s physical health (25.5%) or mental health (18.7%).

Have you gotten enough information, services, or support in the following areas for your child:

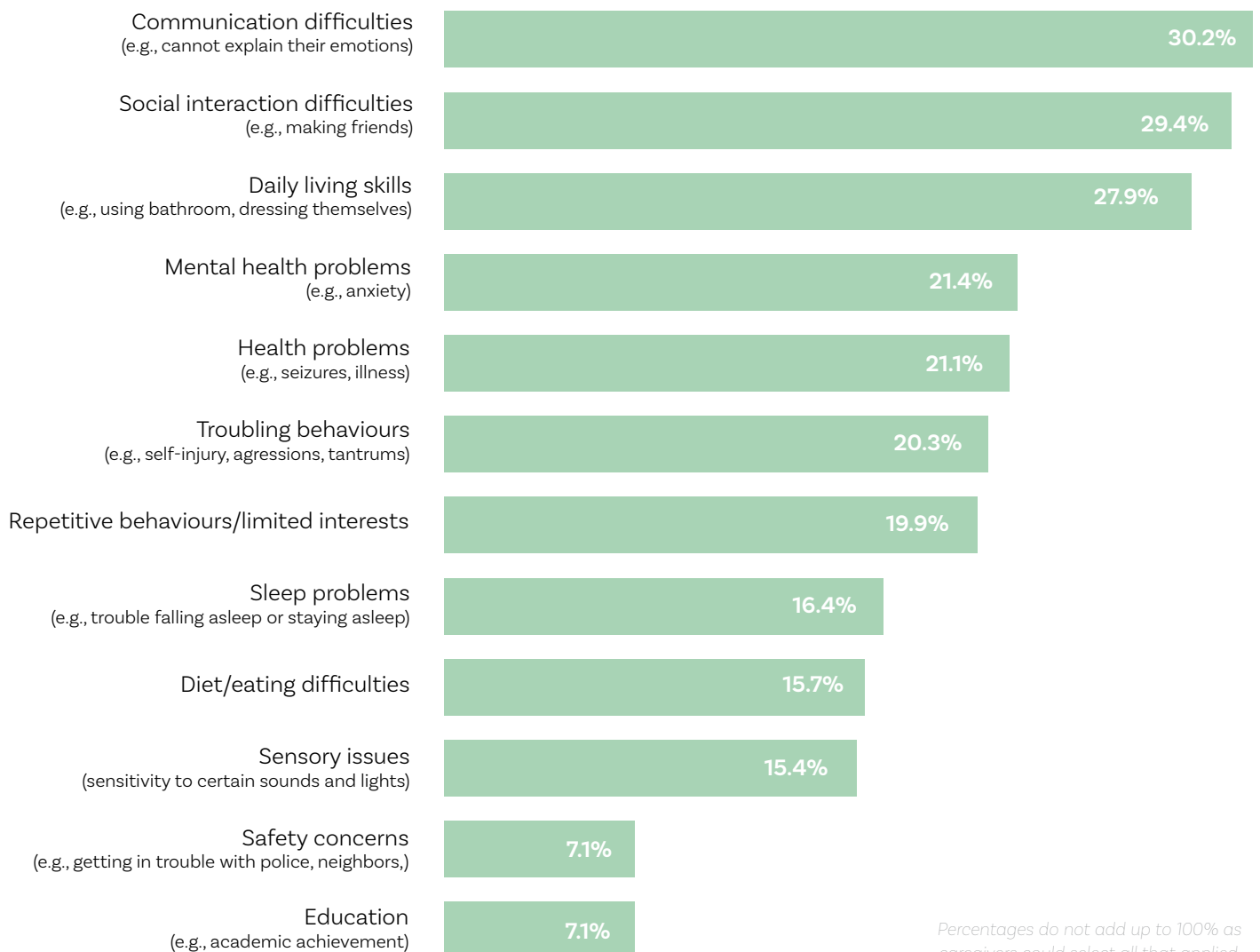


Developmental history and diagnosis of the child

Over half of caregivers (54.5%) indicated it had been them, the primary caregiver, to first notice the concern regarding the development of the child.



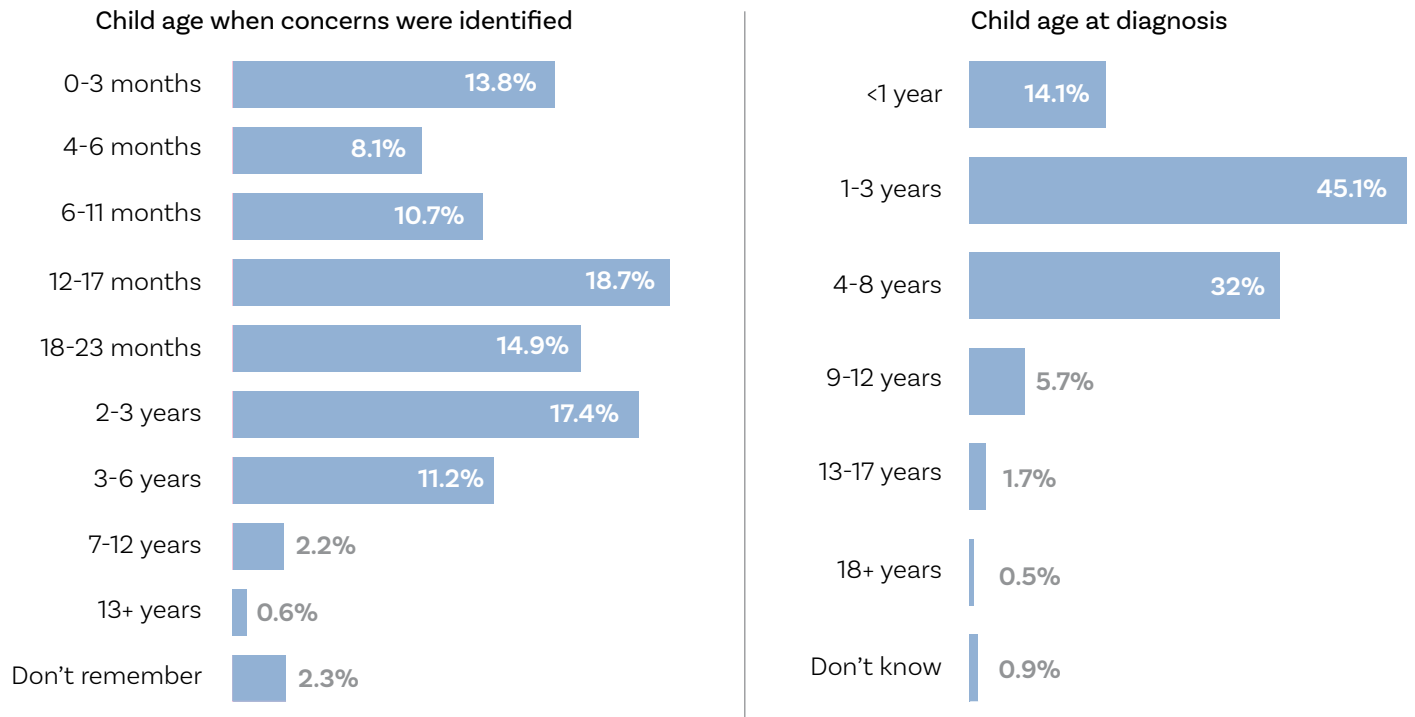
Reasons parent was concerned about child's development



Percentages do not add up to 100% as caregivers could select all that applied.

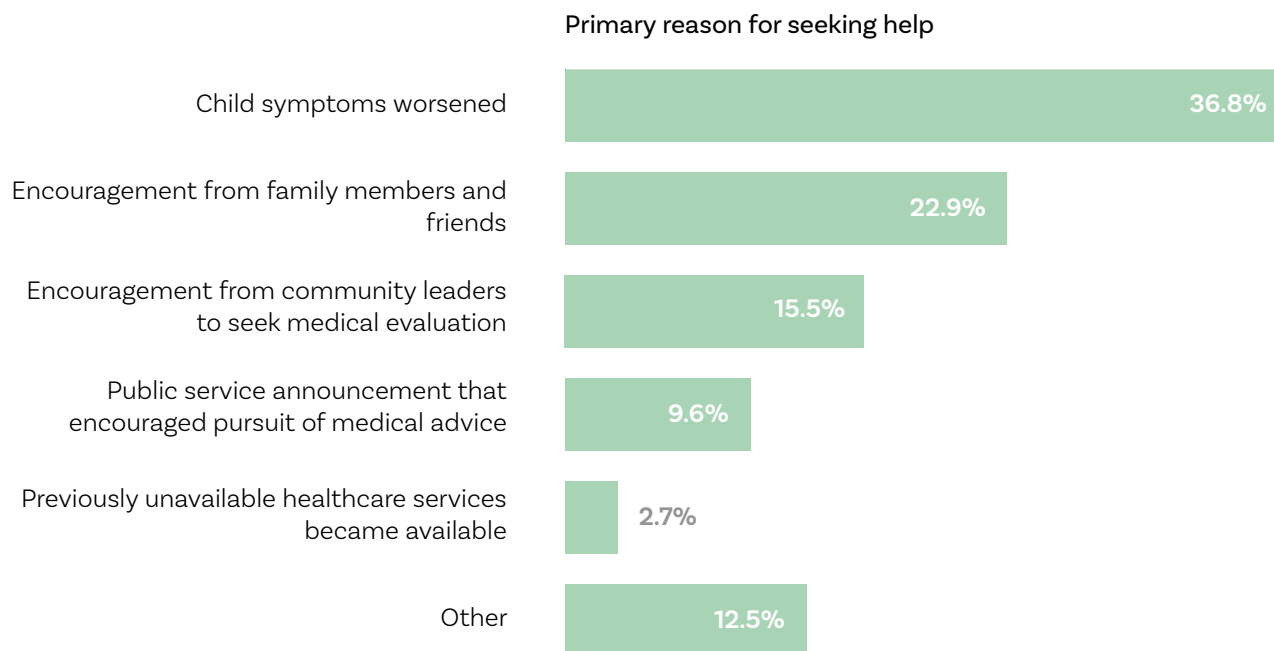
Child age when concerns were identified

Over half of caregivers (66.2%) also indicated the developmental concerns were identified before the child was 2 years of age. Not surprisingly, nearly half (45.1%) indicated the child’s age at diagnosis was 1 to 3 years.



Caregiver’s help-seeking

More than one third (36.8%) of caregivers indicated that the worsening of the child’s symptoms was the primary reason that led them to seek help.



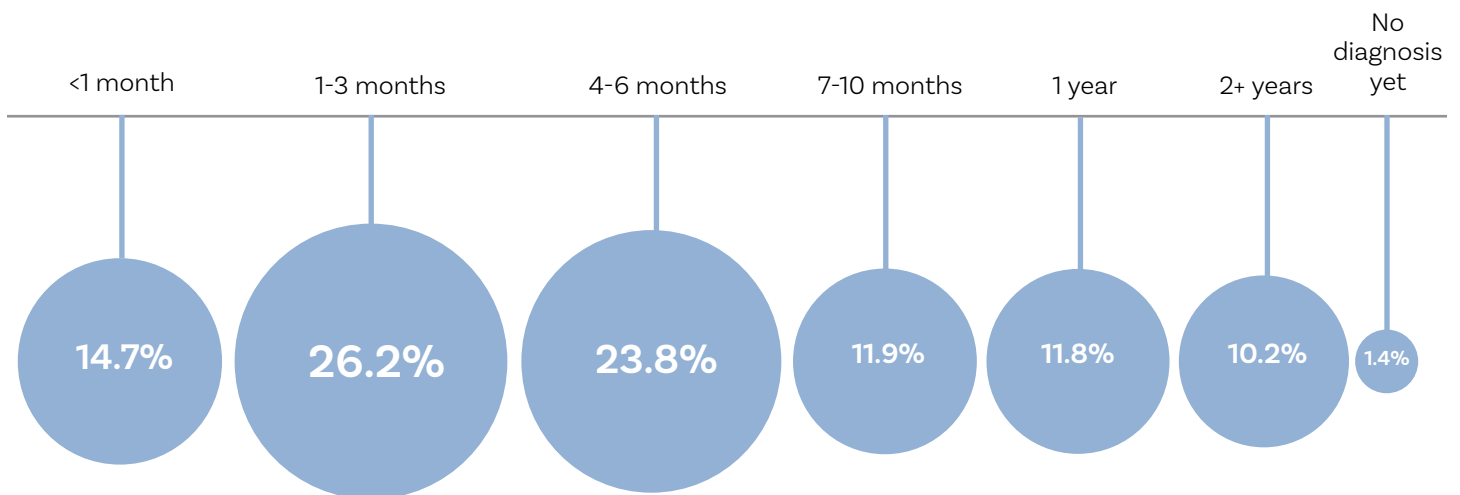
Distance travelled to obtain care

The vast majority of survey caregivers (78.2%) received most of their healthcare services close to the place where they live. However nearly one fifth indicated traveling far within their province to receive the necessary services for their child.

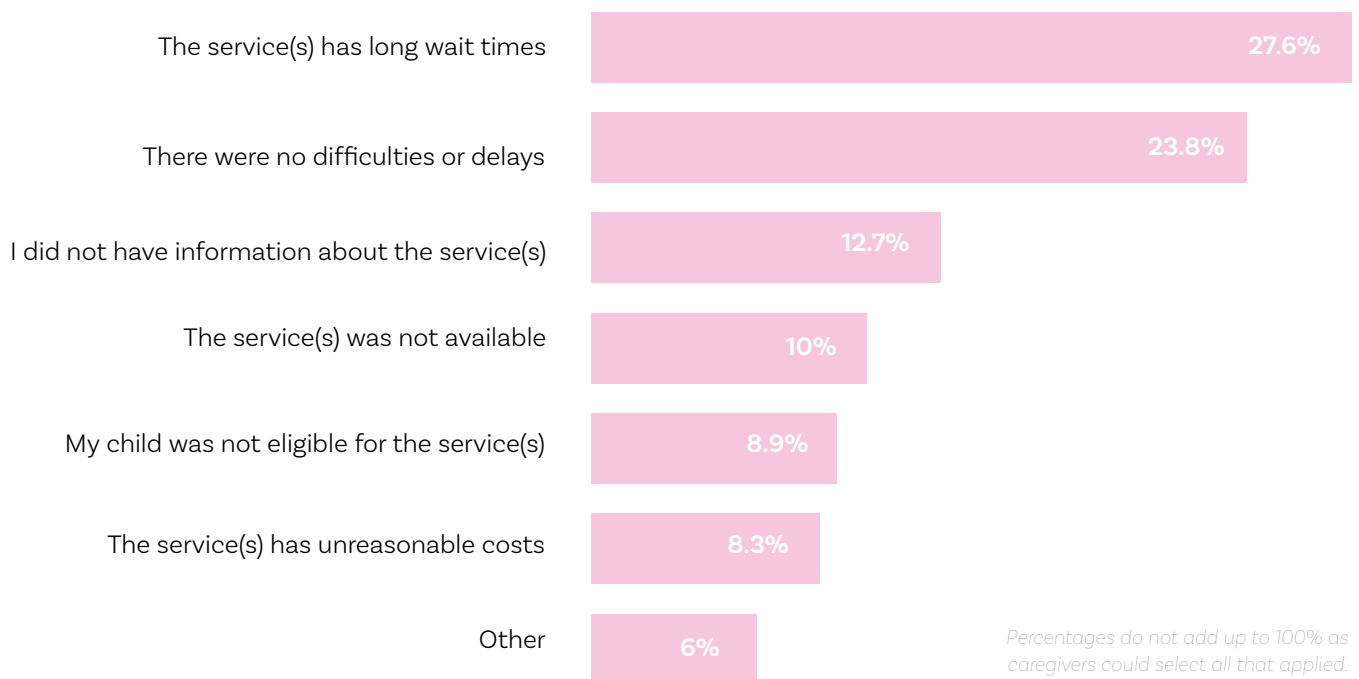


Delay between seeking help and receiving diagnosis

Half of the caregivers reported waiting between 1-6 months between first looking for help due to a concern in development of their child and receiving an official diagnosis. Nearly one quarter (22%) reported one year or more of delay. While 23.8% of participants reported no difficulties or delays between first identification and diagnosis, others reported wait times or lack of information about services as some reasons for a delay.



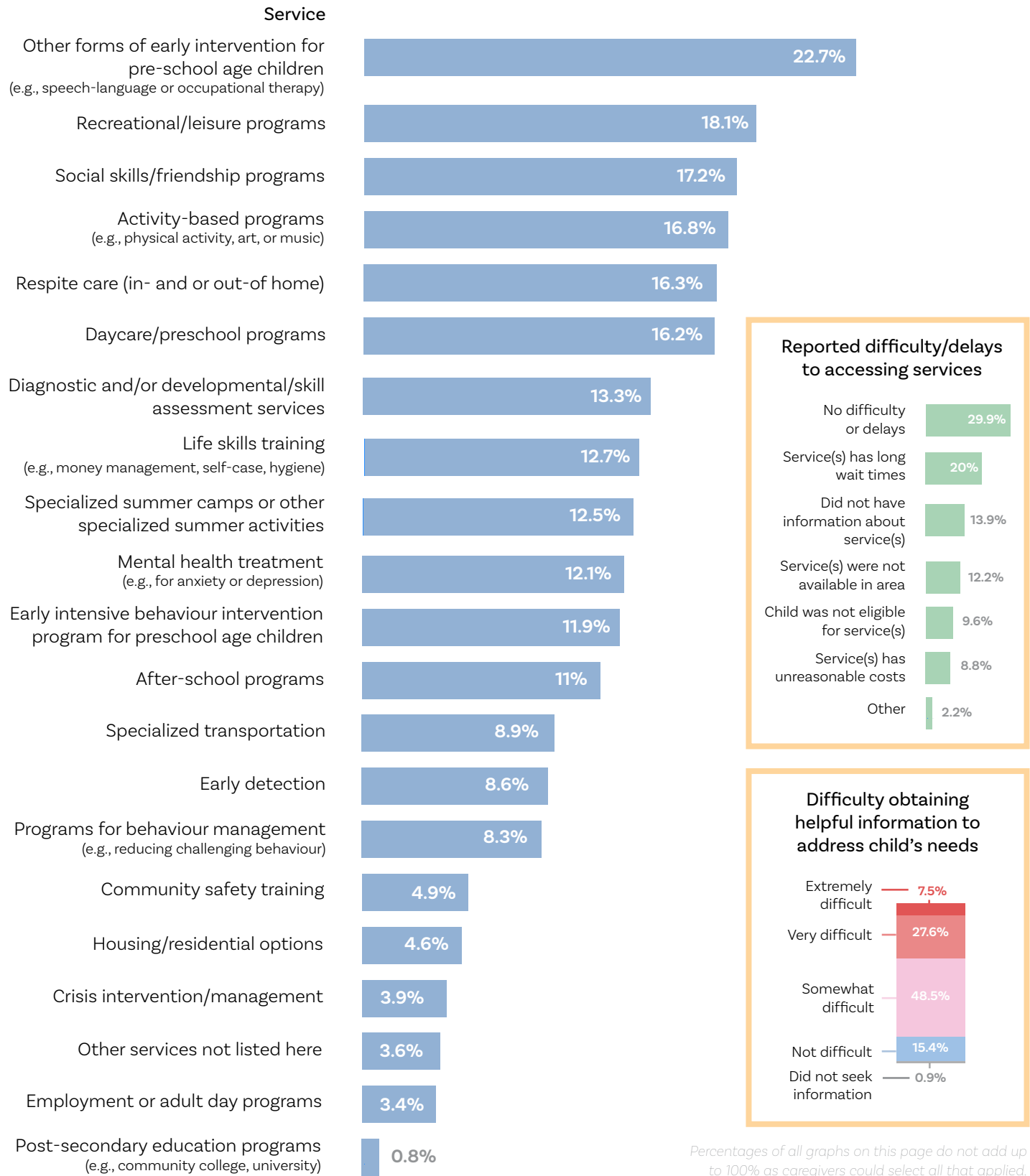
Reasons that resulted in difficulties/delays in receiving diagnosis



Percentages do not add up to 100% as caregivers could select all that applied.

Use of services and obtaining information

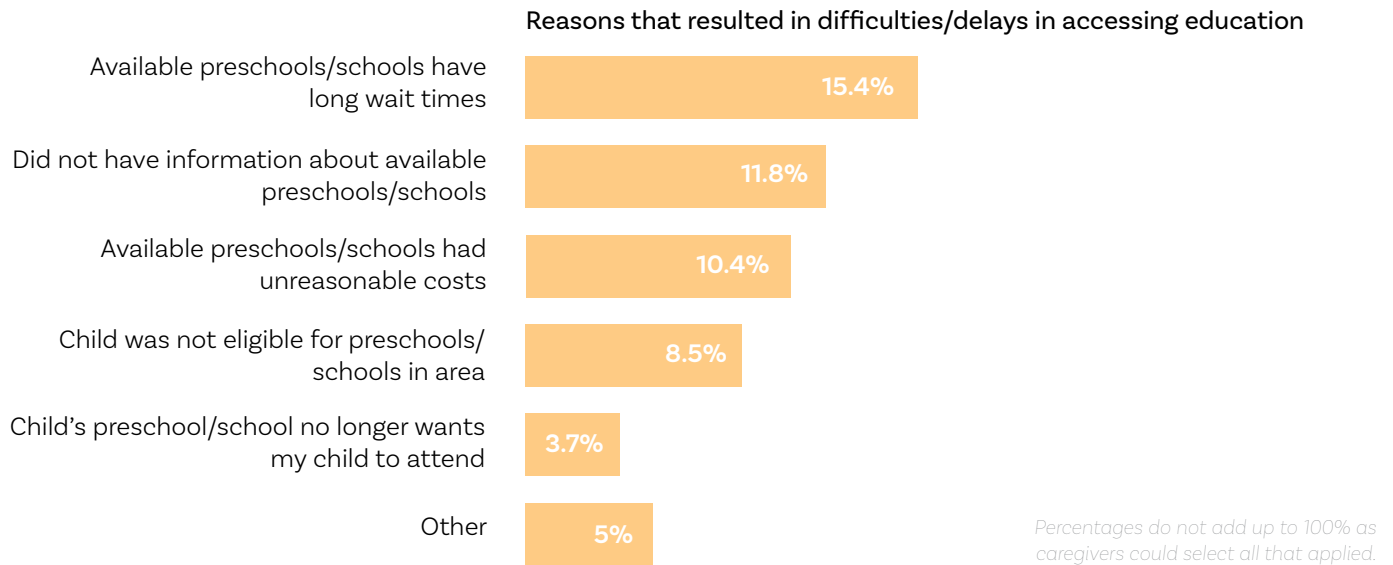
Prior to the pandemic, early intervention programs (22.7%), recreational/leisure programs (18.1%), and social skills programs (17.2%) were the most frequently reported types of programs used. Top three difficulties experienced when accessing these services were: long wait times (20%), insufficient information (13.9%), and unavailable services (12.2%). When asked how difficult it had been to obtain accurate and helpful information on how best to address the child’s needs, 15.4% reported it had not been difficult.



Percentages of all graphs on this page do not add up to 100% as caregivers could select all that applied.

Reasons that resulted in difficulties/delays in accessing education

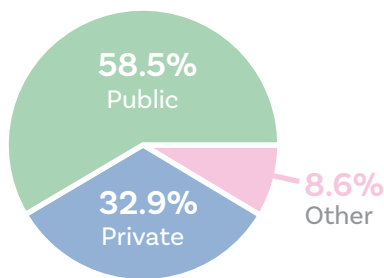
Slightly over one third of caregivers reported no difficulties or delays in accessing adequate educational services for their child with a disability. For others, long wait times (15.4%), lack of information about available schools (11.8%), and unreasonable costs (10.4%) were the top three difficulties reported when accessing educational services prior to the



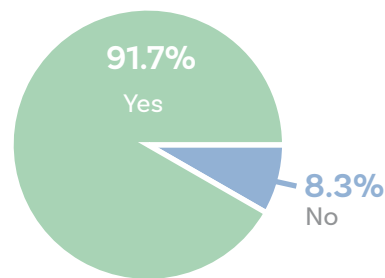
Educational setting

Over half (58.5%) of caregivers indicated their child attended a public preschool/school and the majority (91.7%) reported the school was aware of the child's condition. However, only 26.8% indicated that the school offered additional support for the child.

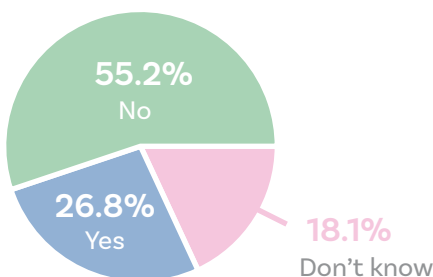
School type attended by child



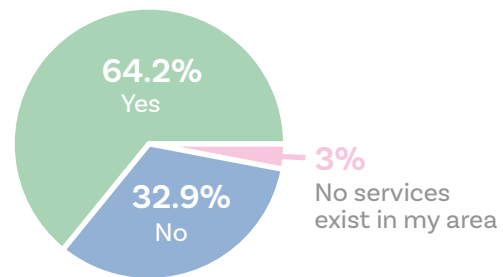
School's knowledge of child's condition



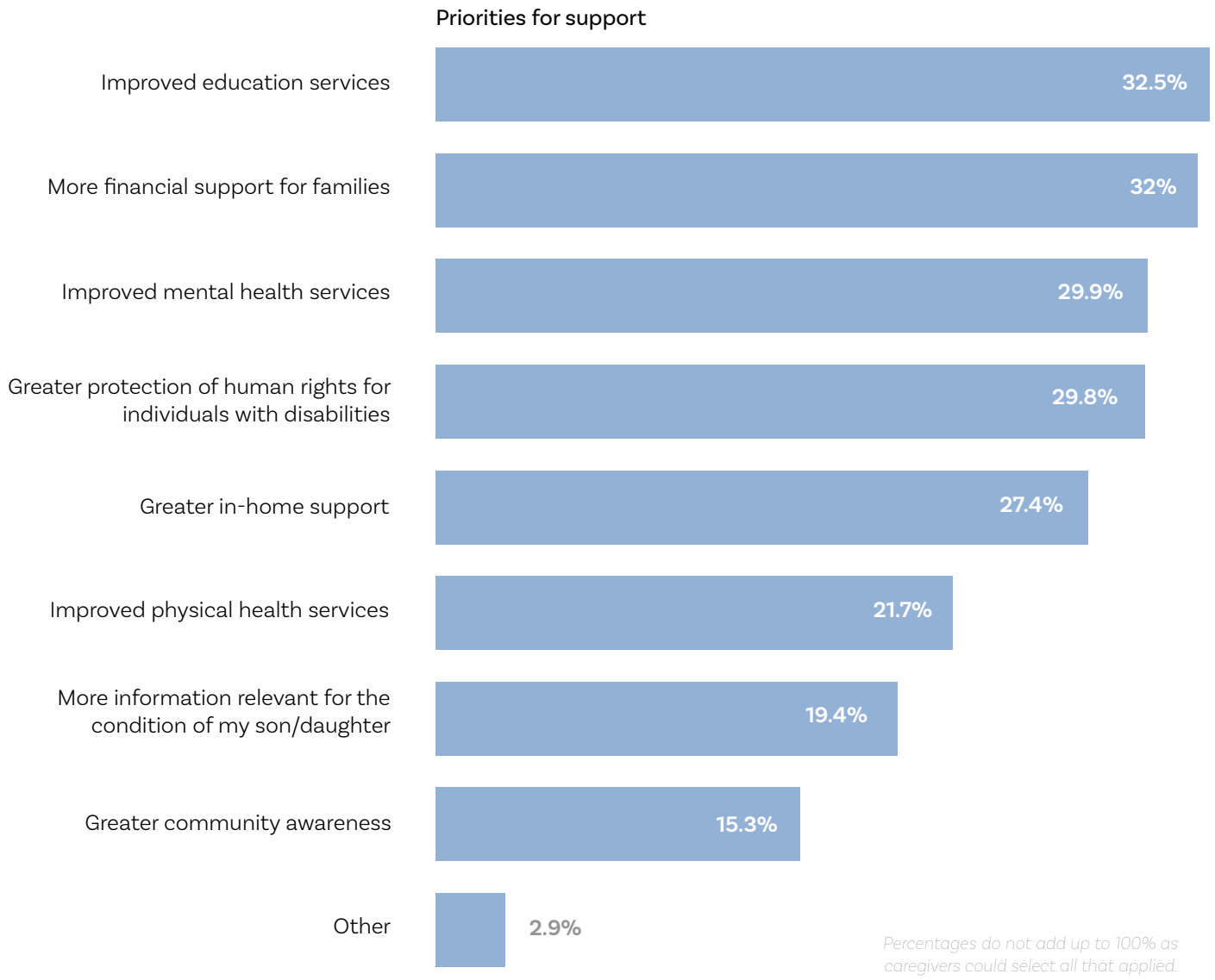
School offered additional support



Received services to manage/support needs of person with a disability



Improved education services (32.5%), financial support (32.0%), and improved mental health services (29.9%) were what caregivers considered to be the top three priorities for support for Canadian families affected by developmental disabilities.



Part 4: Conclusions

The COVID-19 pandemic has had both direct and indirect impacts on children with disabilities and their caregivers. Caregivers reported being worried about their health, the health of the child with the disability, and reported changes (worsening) in their child's behaviour.

Challenges faced by these families included:

1. Maintaining their support networks (regular helpers, family, community)
2. Receiving telehealth services for themselves and regular or telehealth services for their children
3. Accessing information (services/supports available during the pandemic)
4. Obtaining educational plans for schooling their children at home

Prior to the pandemic, survey respondents also experienced difficulties or delays when accessing health and social services, accessing education, or receiving a diagnosis. They also reported it was difficult to obtain information to help them address their child's needs. Thus, the pandemic has brought to light problems that were already existent for these families, amplifying need and enlarging service gaps.

Difficulties experienced may exacerbate the stress families of children with disabilities already experience, can further put them at risk for adverse psychological and physical health, and highlight the need to take prompt action. Systems of care are seldom prepared to appropriately manage public health emergencies such as those imposed by the COVID-19 pandemic in an inclusive way as proposed by the UN CRPD and other normative frameworks. The COVID-19 pandemic has exposed the marginalization and risks that children with developmental disabilities and their families face on a daily basis. It is paramount to consider the unique needs of these families when creating future

emergency responses, and to take advantage of the system's gaps now exposed to improve access and quality of services for these families.

Next steps

We continue to work towards a number of complementary goals:

1. Findings of the Canadian Global Report Survey continue to be actively analyzed focusing on directions and recommendations by stakeholders. These include analyses of potential inequities affecting equity-seeking Canadians such as those with low income, indigenous communities, and/or immigrants.
2. Other analyses are focused on understanding predictors of coping and wellbeing among those with disability. This includes analyses focusing on those who are doing worse than expected and those doing better than expected to inform future services.
3. Dissemination activities are also ongoing to ensure that relevant data are available to decision and policy makers as well as all key stakeholders including individuals with disabilities and organizations who contributed to the report
4. The Canadian Global Report survey was made available to numerous international colleagues who expressed interest. Some are currently collecting data using the survey, creating timely opportunities to make cross-country comparisons, as many continue to experience protracted impacts of the pandemic.

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Employers don't seem to think that a vulnerable child qualifies for a work from home scenario.

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