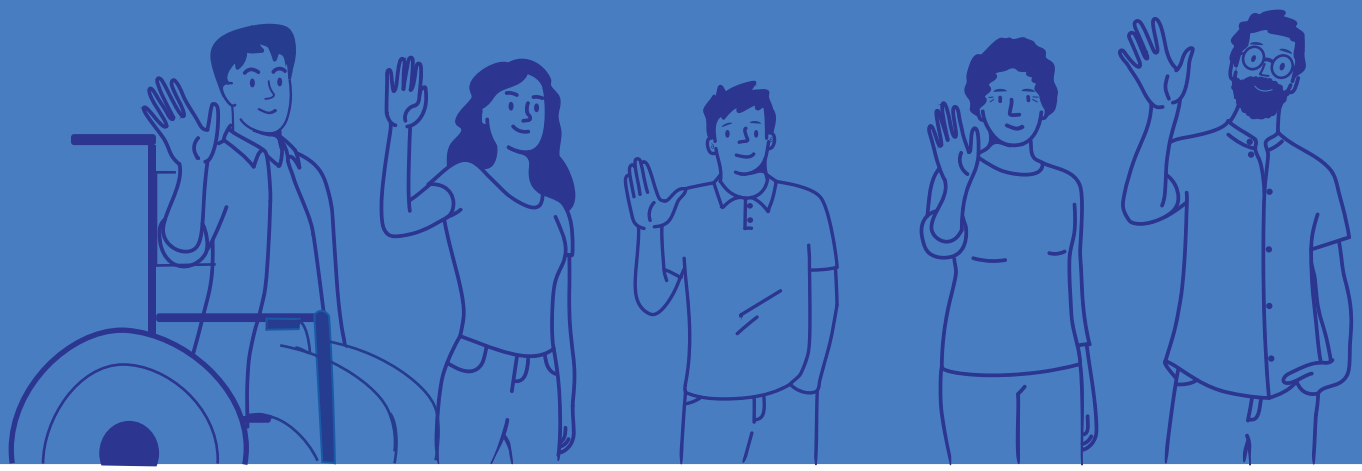
Evolving impacts of the COVID-19 pandemic on autistic people and their caregivers:

Results from the 2023 Pandemic Canadian Autism Needs Assessment Survey



Comprehensive Report, April 2024

autism speaks CANADA

Autism Alliance of Canada | Alliance canadienne de l'autisme

MacART | McMaster Autism Research Team

Advancing autism care through meaningful research

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1 Acknowledgments

The PANCAN Autism Survey and this report were developed in partnership with autistic people, caregivers, Autism Speaks Canada, Autism Alliance of Canada, and McMaster Autism Research Team, with collaboration from Fédération québécoise de l'autisme, Autism Yukon, and Pacific Autism Family Network. We, the survey partners are especially grateful to the autistic adults and caregivers who gave their time to respond to this survey. The following people contributed to developing the survey and this report: Monica Halsey, Mackenzie Salt, Anna Kata, Jill Farber, Jonathan Lai, Deepa Singal, Stelios Georgiades, Lena Trubnikova, and Kathi Cosgrove; and a team of autistic adult and caregiver reviewers including Jo Beyers, Aly Vaillancourt, Joelle Laroch, Grace Braun, Karina Passos, Karrie Daponte, Cristy Mauri, Maranatha Okokon-Bassey, Phuong Nguyen, and others. We would also like to acknowledge the provincial/territorial and other autism organizations across Canada that assisted with disseminating the survey and its findings.

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2 Executive Summary

The objective of the 2023 Pandemic Canadian Autism Needs Assessment (PANCAN Autism) Survey was to better understand the continuing impacts of the COVID-19 pandemic on autistic adults, caregivers (parents) and their autistic children (of any age), living in Canada, including impacts on their experiences of services and supports. It was developed and disseminated in partnership with autistic people, caregivers, Autism Speaks Canada, Autism Alliance of Canada, and the McMaster Autism Research Team (MacART), and the participation of seventeen provincial, territorial, and other autism-focussed organizations across Canada.

The survey respondents included 448 autistic adults (both formally diagnosed, and self-identifying) and 1,082 caregivers, who each answered 60-70 survey questions; 196 respondents who identified as both autistic and caregiver answered questions applying to both respondent types. Caregivers answered questions about themselves and their specific autistic child (of any age), for up to three children, for a total of 975 autistic children.

There were several key findings from this survey:

1. **Changes in access to services and supports were generally accompanied by the same changes to health—worse access came with worsened health.** Changes in access to most types of services and supports over the course of the COVID-19 pandemic were accompanied by changes to general and mental health—those with worse access experienced worsening of these forms of health, while those with improved access experienced improvements. This was consistently true for autistic adults, caregivers, and autistic children. This relationship was also strikingly consistent across many combinations of supports/services and types of health that were asked about in the survey.

2. **Remote delivery of health professional services may be a better idea for autistic adults and caregivers than it is for autistic children**. Remote delivery of most health professional services during the COVID-19 pandemic was more often seen as a good thing (increased accessibility, more happiness) for meeting AUTISTIC ADULTS' and CAREGIVERS' health needs (graphs not shown). But remote delivery for meeting autistic CHILRDREN'S health needs was more often reported on negatively by their caregivers' (more unhappiness). One exception to this was primary care physician services for children's needs—more caregivers reported being happy with their availability via remote delivery compared to those who reported being unhappy.

3. **Caregivers felt certain or somewhat certain that the COVID-19 pandemic slowed overall child development for two thirds of the children they reported on.**

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4. **Caregivers who identify as autistic may have unique needs related to the COVID-19 pandemic compared to non-autistic caregivers**. For example, among respondents to this survey, autistic caregivers were more likely to:
    - Share child caregiving responsibilities in non-conventional ways, such as with another caregiver who is not a parent
    - Experience higher levels of unmet needs for health professional services for their own care
    - Have had increased need for respite care during the pandemic
    - Experience high levels of family distress needing crisis supports
    - Report improvements to mental health over the course of the pandemic (the explanations for this were not studied)

Below is a more comprehensive summary of findings for each of the three types of people reported on: autistic adults, caregivers, and autistic children (of any age). The sections below may be of interest to those seeking further summary of the findings specific to one or more of these groups, or to the topics asked about. Importantly, this summary includes results of the cross-analyses contained in Appendix A of this report. These were analyses of how results from one question varied according to the answers to another question elsewhere in the survey—such as how autistic adults' general health varied by their access to health professional services. The cross-analyses do not appear in the main sections of the report, but are italicized in the summary of findings, below. They are important because some of the key findings above were derived from them.

2.a Summary of findings

Autistic adults

1. About autistic adult respondents

Age. Autistic adults ranged in age from 18-78 years, although only 1.8% were 65 or older.

Gender. Slightly over half (51.3%) identified as women and 42.8% identified as men, which is lower than expected given that autistic males are estimated to outnumber autistic females 3:1.[1] The proportion identifying as non-binary (5.1%) was higher than in the Canadian population (0.1%), consistent with the higher known rates of autism diagnoses among gender-diverse individuals.[2]

Education. Autistic adult respondents had higher levels of education compared to the Canadian population[3] (it is not known what the education levels are in the autistic-only population in Canada).

1 Loomes, R; Hull, L; Mandy, WPL; (2017) What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. Journal of the American Academy of Child & Adolescent Psychiatry, 56 (6) pp. 466-474. 10.1016/j.jaac.2017.03.013.

2 Warrier V, Greenberg DM, Weir E, Buckingham C, Smith P, Lai MC, Allison C, Baron-Cohen S. Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. Nat Commun. 2020 Aug 7;11(1):3959. doi: 10.1038/s41467-020-17794-1.

3 Canadian population data from 2021 Canadian Census. Source: https://www150.statcan.gc.ca/t1/tbl1/en/cv!recreate.action?pid=9810042901&selectedNodeIds=4D4,4D5,4D13,8D1&checkedLevels=0D1,1D1,2D1,4D1,5D1,6D1,6D2,6D3,6D4&refPeriods=20210101,20210101&dimensionLayouts=layout2,layout2,layout2,layout2,layout2,layout2,layout3,layout2,layout2&vectorDisplay=false.

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Geography. Autistic adults from all provinces and territories responded, although proportions were lower than the Canadian population proportions for Ontario and Quebec, and higher for Maritime provinces (excepting PEI).
Indigenous and racial-ethnic identification. Higher proportions identified as white or Indigenous, and lower proportions identified as non-white, compared to the Canadian population. 9.6% were not Canadian citizens by birth.
Diagnostic status. 84.2% reported having a formal autism diagnosis (among whom, 43.2% reported being diagnosed as an adult), while 15.8% self-identified as autistic (44.0% of whom were currently seeking a diagnosis).

2. Diagnosis. Among adults seeking an autism diagnosis, 66.7% felt the pandemic slowed the process of obtaining a publicly-funded diagnosis.

Disability- or autism-related supports. Regarding the different disability- or autism-related supports (including for housing, employment, postsecondary education, communication, finances, and from peers), 56-68% of autistic adults rated their level of unmet needs as moderate-to-extremely high. This percentage was highest for financial supports. Perceived change in access to these supports since the pandemic was mixed—with roughly comparable numbers reporting improvement and worsening.
Health professional services. For health professional services (including primary care physicians, specialist physicians, psychological and psychotherapy services, physio- or occupational therapists, speech and language pathologists, and social workers), the percentage of respondents rating their needs as moderate-to-extremely high was highest for specialist physicians (70.1%) and psychological and psychotherapy services (72.8%).
More autistic adults believed their access to most health professional services worsened during the COVID-19 pandemic compared to the number who believed it improved (with the exception of speech and language pathologists).
Care navigation supports. 68.9% of autistic adults rated their unmet needs for care navigation supports as moderate-to-extremely high.
Shift of health professional services to remote delivery. A higher percentage of autistic adults reported that the shift of health professional services to remote delivery improved access, compared to those that reported it worsened access. Similarly, a higher percentage reported being happy with the availability of remote delivery for all professionals than being unhappy with it.

3. *COVID-19 pandemic effects on autistic adults' health and well-being*

General health. More autistic adults reported that their general health worsened since the beginning of the COVID-19 pandemic than those who reported that it improved.

Higher-than-expected proportions of autistic adults reported improved general health with improved access, and worsened general health with worsened access, to disability- or autism-related supports or health professional services. This relationship was true for all types of supports and health professional services.

Long-term health conditions. 44.2% of autistic adults reported currently having one or more long-term health conditions (other than autism). Mood and anxiety disorders were the most common (67.2%). 33.2% of those with long-term health conditions reported onset of at least one condition since the COVID-19 pandemic, and 50.5% reported overall worsening of their conditions since the start of the pandemic.

Healthy habits. More autistic adults reported worsening of both their level of daily physical activity and sleep habits than those who reported improvements in these self-care habits. However, the percentage who reported eating unhealthier was roughly the same as those who reported eating healthier.

Mental health. Roughly twice as many autistic adults reported worsening of all forms of mental health that were asked about (stress, anxiety, depression, and symptoms from past experiences of traumatic events) compared to the percentage who reported improvements.

Higher-than-expected proportions of autistic adults generally reported improved mental health with improved access, and worsened mental health with worsened access to disability- or autism-related supports—with some exceptions. This relationship was less consistent for some forms of mental health (e.g., symptoms from past experiences of traumatic events) and for some types of disability- or autism-related supports (e.g., peer supports). Meanwhile, higher-than-expected proportions of autistic adults reported improved mental health with improved access, and worsened mental health with worsened access, to each type of health professional service. This was true for all forms of mental health, and all types of health professional services.

Other aspects of mental and social functioning. More autistic adults reported worsening from before the COVID-19 pandemic (compared to those who reported improvement) of the following aspects of mental and social functioning: ability to regulate emotions, frequency of meltdowns or shutdowns, ability to mentally focus or concentrate, quality of important relationships, and satisfaction with personal social life. More also reported worsening of different aspects of loneliness.

Postsecondary education. 23.9% of autistic adult respondents reported being enrolled in a postsecondary education program during the COVID-19 pandemic. Of those, 39.6% reported interrupting their enrollment at some point due to the COVID-19 pandemic; 72.2% of this sub-group further reported not resuming enrollment.

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Employment. 74.9% of autistic adult respondents reported being employed at some point during the COVID-19 pandemic. Of those, 71.6% reported fully interrupting their employment at some point due to COVID-19 pandemic; 6.0% of this subgroup further reported not resuming employment.

Caregivers

1. About caregiver respondents

Gender. More caregiver respondents were women than men (by a ratio of approximately 4:1).
Education. Caregiver respondents had higher levels of education compared to the Canadian population (more so than the autistic adult respondents).
Geography. Caregivers from all provinces and territories responded, although proportions were lower than the Canadian population proportions for Quebec, and higher for Ontario and Maritime provinces (excepting PEI).
Number of autistic children. 13.9% had two or more autistic children under their care. 28.0% reported being solely or almost solely responsible for the caregiving responsibilities.
Indigenous and racial-ethnic identification. Slightly higher proportions identified as white or Indigenous, and slightly lower proportions identified as non-white, compared to the Canadian population. 20.5% were not Canadian citizens by birth.
Experience navigating care. About half (49.3%) had many (8+) years experience navigating autism-related care, while 4.1% had 1 or fewer years of experience. Caregivers reported spending an average of 18.6 hours per week navigating and supporting autism-related care for their child(ren).
How caregiving situation varied by caregiver autistic status. *Higher-than-expected proportions of autistic caregivers reported sharing caregiving responsibilities in non-conventional ways (i.e., with at least one other caregiver who is not considered a parent [e.g., grandparent, other guardian], or with the child's other parent who lives elsewhere [e.g., child spends some nights with their other parent each week]). Lower-than-expected proportions of autistic caregivers reported being a solo parent or sharing caregiving responsibilities in conventional ways (with the child's other parent who lives in the same house).*

2. *COVID-19 pandemic effects on caregivers' services and supports*

Health professional services. For health professional services used for their own care (including primary care physicians, specialist physicians, psychologist and psychotherapeutic service providers, physio- and occupational therapists, and social workers), the proportions of caregivers rating their needs as moderate-to-extremely high were highest for psychological and psychotherapy services (69.0%).
When comparing autistic to non-autistic caregivers, higher-than-expected proportions of autistic caregivers consistently reported "moderately to extremely high" unmet needs for all types of health professional services.
Access to all health professional services, meanwhile, was perceived to worsen during the pandemic by considerably more caregivers than those who perceived it to improve.
Care navigation supports. 73.5% of caregivers rated their unmet needs for care navigation supports as moderate-to-extremely high.
When comparing autistic to non-autistic caregivers, higher-than-expected proportions of autistic caregivers reported "low or no" unmet needs for care navigation supports.
Respite. 73% of caregivers reported an increase in need for respite care at some point because of COVID-19 pandemic.
Higher-than-expected proportions of autistic caregivers reported having an increased need for respite, while higher-than-expected proportions of non-autistic caregivers reported having no increased need.
Shift of health professional services to remote delivery. More caregivers reported that the shift of some health professional services (specialist physicians, physio- and occupational therapists, speech and language pathologists, and social workers) to remote delivery worsened access (compared to those who reported it improved access). Similar percentages of caregivers reported improved and worsened access for primary care physicians, or psychologist and psychotherapeutic service providers. More reported being happy with the availability of remote delivery for primary care physicians, specialist physicians, and psychologist and psychotherapeutic service providers than reported being unhappy.

3. *COVID-19 pandemic effects on caregivers' health and well-being*

General health. More caregivers reported that their general health worsened since the beginning of the COVID-19 pandemic compared to those who reported that it improved.
Higher-than-expected proportions of caregivers reported improved general health with improved access, and worsened general health with worsened access, to disability- or autism-related supports or health professional services. This relationship was true for all types of supports and health professional services.

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Healthy habits. More caregivers reported worsening in the level of their daily physical activity, their sleep habits, and healthiness of their eating habits than those who reported improvements.
Level of family distress. Level of family distress improved from the most stressful part of the COVID-19 pandemic for 55.5% of respondents, and worsened for 22.7% of respondents.
Higher-than-expected proportions of autistic caregivers reported the highest levels of family distress and lower levels of mild distress, at the time of the survey. There was no significant variation by caregiver autistic status in the level of family distress experienced at what caregivers' felt was the most stressful part of the COVID-19 pandemic. This suggests families of autistic caregivers may currently have higher needs for crisis supports than families of non-autistic caregivers.
Caregiver mental health. Over twice the percentage of caregivers reported worsening of all forms of mental health that were asked about (stress, anxiety, depression, and symptoms from past experiences of traumatic events) compared to those who reported improvements.
Higher-than-expected proportions of caregivers reported improved mental health with improved access to each type of health professional service; and worsened mental health with worsened access to each type of health professional service. This was true for all forms of mental health, and all types of health professional services. Changes in mental health since the pandemic also varied by caregiver autistic status: Higher-than-expected proportions of autistic caregivers reported improved mental health (of all types) from before COVID-19 pandemic to now. More caregivers reported increases in the use both of positive and of negative coping strategies, from worst part of the COVID-19 pandemic to now.
Social life. The COVID-19 pandemic had mixed effects (both improvement and worsening) on ability to spend time with friends or other important people.
Employment. 73.9% of caregivers reported being employed at some point during the COVID-19 pandemic. Of those, 49.9% reported fully interrupting their employment at some point due to COVID-19 pandemic; 11.7% of this subgroup further reported not resuming employment.

Autistic children

1. About the autistic children reported on

Age. Of the autistic children reported on, 11.9% were aged 5 years or younger, 65.1% were 6-17 years, and 23% were adult-aged.
Gender. 72.1% identified as boys/male and 26.5% identified as girls/female, which may be expected given that autistic males are estimated to outnumber autistic females 3:1.[1] 1.5% identified as non-binary or questioning their gender, which is higher than the proportion of non-binary persons in the Canadian population (0.1%).

1 Loomes, R; Hull, L; Mandy, WPL; (2017) What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. Journal of the American Academy of Child & Adolescent Psychiatry, 56 (6) pp. 466-474. 10.1016/j.jaac.2017.03.013.

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Level of support needs. Proportions of children with each of the three levels of parent-rated support needs were 55.7% (lowest level), 23.7% (intermediate level), and 20.6% (highest level).
Age of diagnosis. 68.1% of children were diagnosed between the ages of 1-5 years, and 20.8% were diagnosed between 6-10 years.
Higher-than-expected proportions of autistic caregivers reported their child(ren) being diagnosed at younger ages, while higher-than-expected proportions of non-autistic caregivers reported their children being diagnosed at older ages. This may suggest that autistic caregivers in this sample became aware their child was autistic at younger ages than the non-autistic caregivers did, which may be because parents are often the ones who initiate the diagnostic process after noticing a developmental difference in their child.[1]

2. COVID-19 pandemic effects on autistic children's services and supports

Diagnosis. Caregivers felt the pandemic slowed the process of obtaining a publicly-funded diagnosis for 59.4% of children (among children for whom their caregivers were in the process of seeking a diagnosis during the COVID-19 pandemic).
Autism-or development-related supports. For autism- or development-related supports (including behavioural therapy services/programs, social skills groups/programs, speech and language therapy, communication supports, and education system accommodations/supports), the percentages of children whose level of unmet needs was rated to be moderate-to-extremely high ranged from 59.7-74.8%. This percentage was highest for social skills groups/programs. Access to each of these supports was perceived to have worsened since the pandemic for substantially more children (compared to those for whom it was perceived to have improved). The same pattern was observed for adult-child–relevant supports (including housing, employment, postsecondary education, peer-related, and financial). The level of unmet need, however, was greater for these adult supports than it was for child supports.
Health professional services. For health professional services (including primary care physicians, specialist physicians, psychological and psychotherapy services, physio- or occupational therapists, speech and language pathologists, and social workers), the proportions of children whose needs were rated as moderate-to-extremely high were highest for psychological and psychotherapy services (64.9%). Access to all health professional services was perceived to worsen for a higher percentage of children than those for whom it was perceived to improve.

1 Gentles, S. J., D. B. Nicholas, S. M. Jack, K. A. McKibbon and P. Szatmari. 2020. "Coming to Understand the Child Has Autism: A Process Illustrating Parents' Evolving Readiness for Engaging in Care." Autism 24(2):470-83. doi: 10.1177/1362361319874647.

Shift of health professional services to remote delivery. For most health professional services (specialist physicians, psychologist and psychotherapeutic service providers, physio- and occupational therapists, speech and language pathologists, and social workers; but not primary care physicians), the shift to remote delivery worsened access for more children. For primary care physicians, a higher percentage of caregivers reported being happy with availability via remote delivery than those who reported being unhappy with it for meeting their child's needs.

3. COVID-19 pandemic effects on autistic children's health and well-being

General health. General health worsened since the beginning of the COVID-19 pandemic for more children than those for whom it improved.
Higher-than-expected proportions of children were reported to have improved general health with improved access, and worsened general health with worsened access, to autism- and development-related supports or health professional services. This was consistently true for all types of supports and health professional services.
Healthy habits. More children were reported to have worsening in the level of their daily physical activity, sleep habits, and healthiness of eating compared to the percentage for whom improvements were reported.
Mental health. More children were reported to have worsening in their mental health compared to the percentage for whom there was improvement. This was true for all forms of mental health (stress, anxiety, depression, and symptoms from past experiences of traumatic events).
Higher-than-expected proportions of children were reported to have improved mental health with improved access, and worsened mental health with worsened access, to autism- and development-related supports or health professional services. This was true for all forms of mental health, and all types of autism- and development-related supports or health professional services.
Other aspects of mental and social functioning, and development. The percentage of children for whom there was worsening in cognitive functioning, was greater than those for whom there was improvement. The same was true for frequency of meltdowns, frequency of engaging in self-harm, ability to mentally focus or concentrate, ability to meet academic demands (school), social development, and daily living skills in the home. For 66.7% of children, caregivers reported feeling certain or somewhat certain that the COVID-19 pandemic had slowed their overall rate of development.

3 Introduction

The *2023 Pandemic Canadian Autism Needs Assessment (PANCAN Autism) Survey* investigated the ongoing impacts of the COVID-19 pandemic on autistic* adults, and caregivers (parents) and their autistic children (of any age), living in Canada. This survey was developed in partnership with autistic people, caregivers, Autism Speaks Canada, Autism Alliance of Canada, and the McMaster Autism Research Team (MacART). Fédération québécoise de l'autisme, Autism Yukon, and Pacific Autism Family Network participated in development of the survey and this report.

Another survey on the impacts of the COVID-19 pandemic on the autism community across Canada was conducted in 2020, at an earlier stage of the pandemic.[1] Some of the earlier effects of the COVID-19 pandemic (including pandemic response measures) on autistic people and their caregivers appear to be long-lasting, although empirical knowledge of this is limited.

The Purpose

The purpose of this survey was therefore to develop a more comprehensive understanding the continuing impacts of the COVID-19 pandemic on autistic adults and on caregivers of autistic children (of any age) in Canada, including impacts on their experiences of services and supports. The results in this report will be helpful to inform government, service organizations, and members of the autism community of the ongoing needs and experiences of autistic people and their caregivers in Canada that have resulted from the COVID-19 pandemic.

How the survey was done

The survey was promoted across Canada via social media and targeted outreach (e.g., emailed newsletters) with the help of numerous provincial and territorial autism organizations. The survey was available online, in English and French, from October 17 to November 20, 2023. As an incentive, respondents could enter a random draw for the chance to win a $50 gift card. Respondents in targeted locations were offered support to complete the survey by other means to overcome barriers to access (e.g., completing by telephone).

Types of respondents and people reported on

There were two survey versions, one for each of two different **respondent types:**

1. Autistic adults
2. Caregivers of autistic children

Autistic adults were asked to report on themselves. Caregivers were asked to report on themselves and on their dependent autistic child(ren), regardless of the child's age. This could include any adult children under parental care.

**A note about language: The developers of this survey and survey report respect that different people have different preferences for identity-first ("autistic person") versus person-first ("person with autism") language for referring to autistic people. For consistency, we have chosen to use identity-first language throughout since studies have shown this is the preference of most autistic people. We also respect the stylistic decision by some to capitalize the word "Autistic" in some cases to recognize people who identify as belonging to the autistic community. However, given variation in appropriateness of capitalization for this purpose, we have chosen to keep autistic uncapitalized throughout for consistency.*

1 Salt, M., & Soliman, P. (2020). A Portrait of a Community through Crisis: Results from the Pandemic Canadian Autism Needs Assessment Survey (Technical Report Version 1.0). Autism Speaks Canada.

3 Introduction

(Note: the words “child” and “children” are used in this report to refer to the relationship to the caregiver, and not to age.)

Respondents to each survey answered 60-70 survey questions, which took approximately 25-35 minutes for most people to complete. Those who identified as both caregivers of autistic children AND as autistic adults were asked to complete both versions of the survey (answering overlapping demographics and content questions only once). They therefore also answered questions on their autistic children.

This meant there were three groups of people reported on:

1. Autistic adults (self-reported)
2. Caregivers of autistic children (self-reported)
3. Autistic children of any age (reported on by their caregivers)

Caregivers could complete questions for up to three children with an autism diagnosis under their care. The child results in this report are therefore about individual autistic children. Some caregivers opted not to complete any questions about their children, and only reported about themselves. Caregivers with multiple autistic children were asked to start by completing questions for the child under their care with the highest support needs.

Autistic adults who were never diagnosed as a child can encounter numerous barriers to accessing diagnostic assessments later in life. As a result, many autistic adults seeking an autism diagnosis experience long delays in obtaining one, and may continue to live without a formal autism diagnosis. Therefore, this survey was open to any adult identifying as autistic, whether or not they were formally diagnosed by a qualified professional.

Other important information for interpreting the survey results

- Respondents could choose not to answer questions if they preferred. As a result, the number of respondents for each question varies, and can be lower than the total number of eligible respondents.
- The number of respondents for each question is provided as (n=), which represents the denominator for the percent values reported.
- The people who responded to this survey represent only a small proportion of the overall population of the different types of people reported on who live in Canada (autistic adults, caregivers of autistic children, the autistic children of participating caregivers). As a result, certain important characteristics (e.g., income level, literacy level) may be over- or under-represented in the sample of respondents when compared to the overall population. The results reported here should not be interpreted as accurately representing the overall populations of these groups in Canada.

3 Introduction

Where autistic adults, caregivers, or autistic children are mentioned in this report, it is important to know that we are referring specifically to those reported on by survey respondents, and not to overall populations.

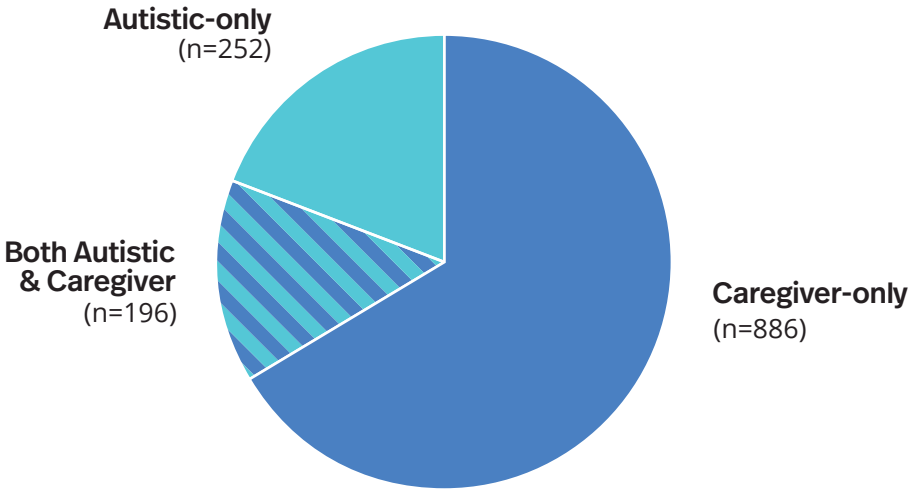
- Reference to Canadian population demographics have been provided in some cases for reference only. It is important to be aware that for some characteristics, we would expect the autistic population to vary from the Canadian population (e.g., gender identity). These Canadian population data are therefore not intended to support judgments about representativeness of the survey sample with respect to the complete populations of autistic adults, caregivers, or autistic children, living in Canada. Judgments about representativeness would require comparisons specifically to overall autistic populations in Canada, which were not available.
- For graphs that show three rating levels (e.g., worsened, unchanged, improved), and a fourth level for unsure, we use "traffic light" colouring to help interpretation:
  - Red (top colour): Undesirable
  - Yellow (middle colour): Neutral
  - Green (lower colour): Desirable
  - Grey (bottom): Unsure
- For questions referring to "now," this was from the respondent's perspective at the time of survey completion when it was live (October 17 to November 20, 2023).

4.0 Results

Number of respondents

In total, 1,334 people completed the survey (completing at least one content question after the demographics section):

- 448 autistic adults, of whom 196 also completed the survey as the caregiver of one or more autistic children of any age.
- 1,082 caregivers, of whom 196 mentioned above also completed the survey as an autistic adult.



Number of autistic children of any age reported on by caregivers

975 autistic children were reported on by 902 caregivers (180 caregivers did not answer child questions). Of these, 902 were the first child that a caregiver reported on, 69 were the second child being reported on, and 4 were the third child being reported on.

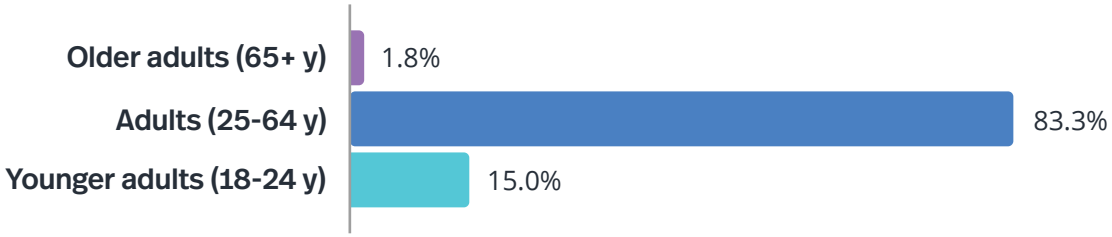
This number of autistic children reported on represents 79.0% of the total number of autistic children that caregivers reported having under their care (n=1,234).

4.1 Autistic Adults

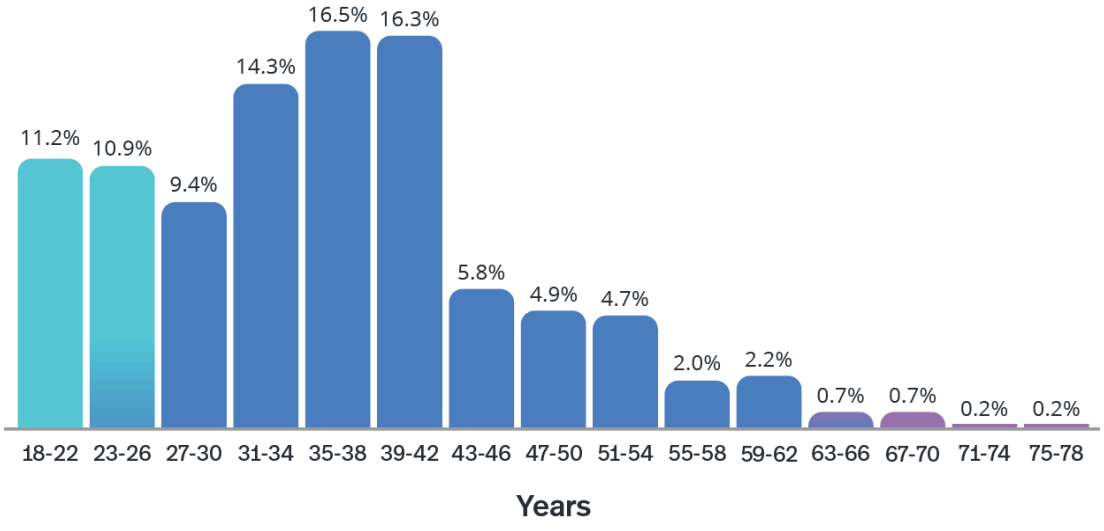
4.1.a About the Autistic Adults Who Responded

Basic demographics

- Age distribution (n=448)
  - By type of adult

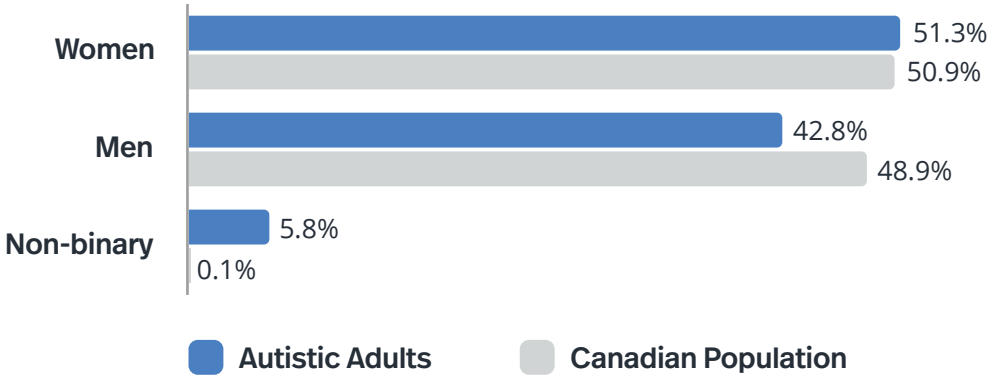


  - By age grouping



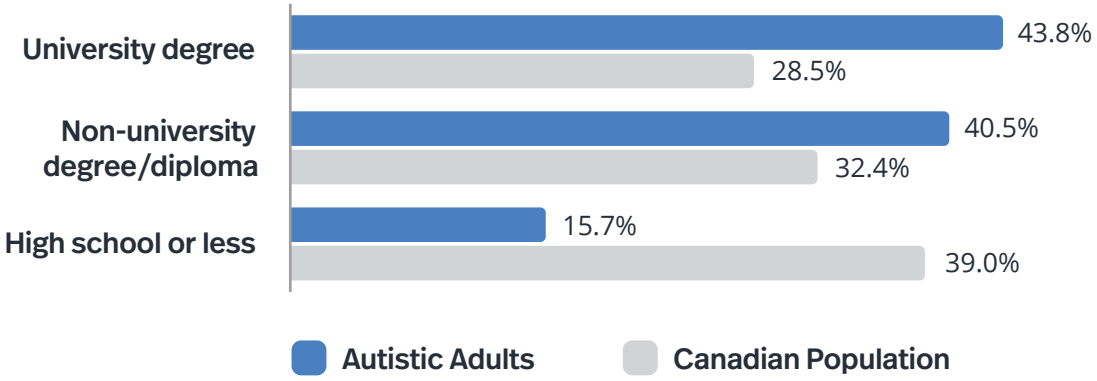
4.1 Autistic Adults

- Gender (n=446)



Canadian population data from Canada Census 2021 (source: https://www150.statcan.gc.ca/n1/daily-quotidien/220427/t002b-eng.htm)

- Education level (n=447)

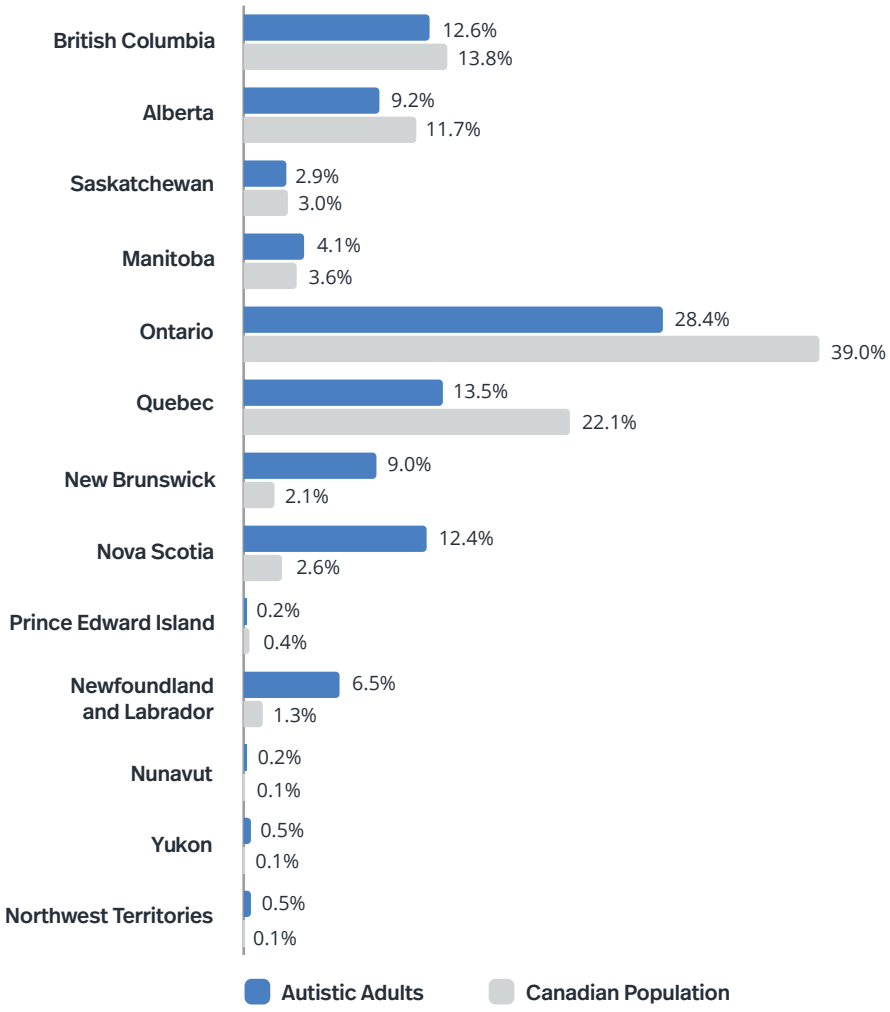


**"Non-university degree or diploma," includes those reporting having completed college, CEGEP or other non-university certificates or diplomas, or some college or university. Canadian population data from 2021 Canadian Census. Source: https://www150.statcan.gc.ca/t1/tbl1/en/cv!recreate.action?pid=9810042901&selectedNodeIds=4D4,4D5,4D13,8D1&checkedLevels=0D1,1D1,2D1,4D1,5D1,6D1,6D2,6D3,6D4&refPeriods=20210101,20210101&dimensionLayouts=layout2,layout2,layout2,layout2,layout2,layout2,layout3,layout2,layout2&vectorDisplay=false*

4.1 Autistic Adults

Geography and Language

- Province/Territory of residence (n=444)



- 15.1% of respondents (n=444) live in a wide-area rural region*

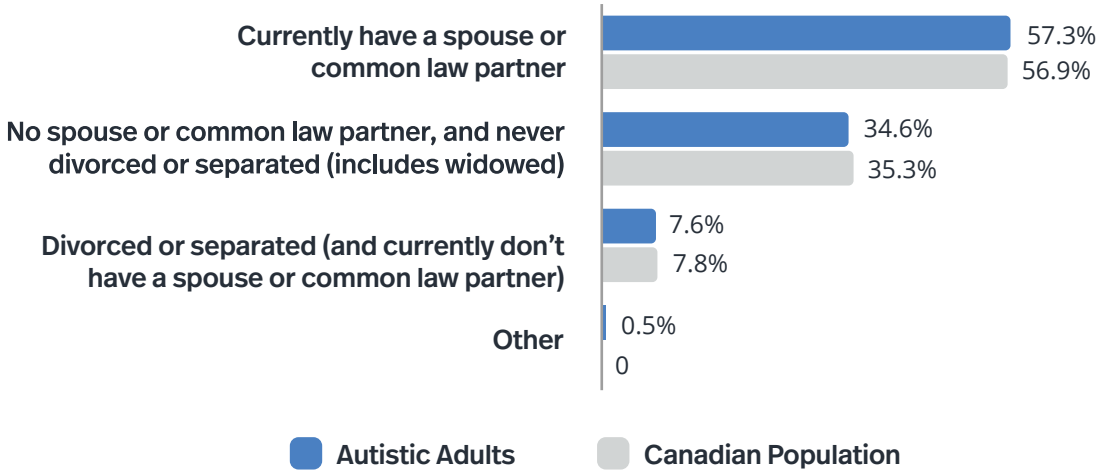
- Languages most often used at home (n=447)
  - English 89.7%
  - French 8.3%
  - Other Languages 2.0%

**Wide-area rural region is based on the second digit of the postal code and provides only a rough estimate of rurality. There was not enough information to differentiate whether people lived in urban or suburban areas.*

4.1 Autistic Adults

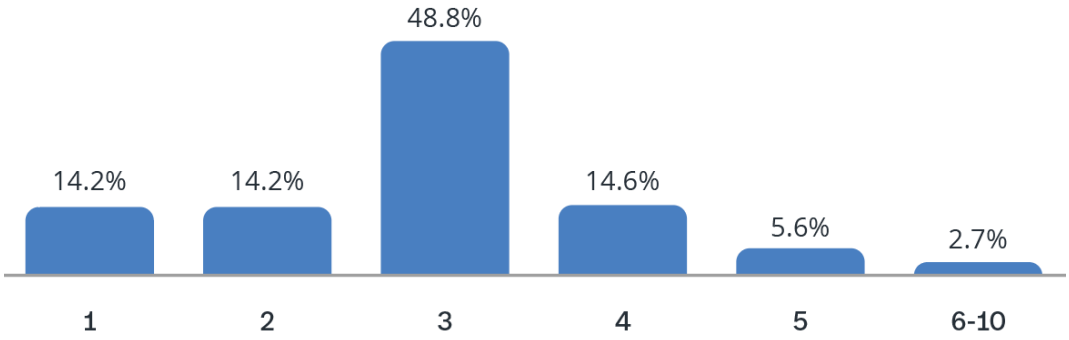
Family Structure

- Marital Status (n=436)

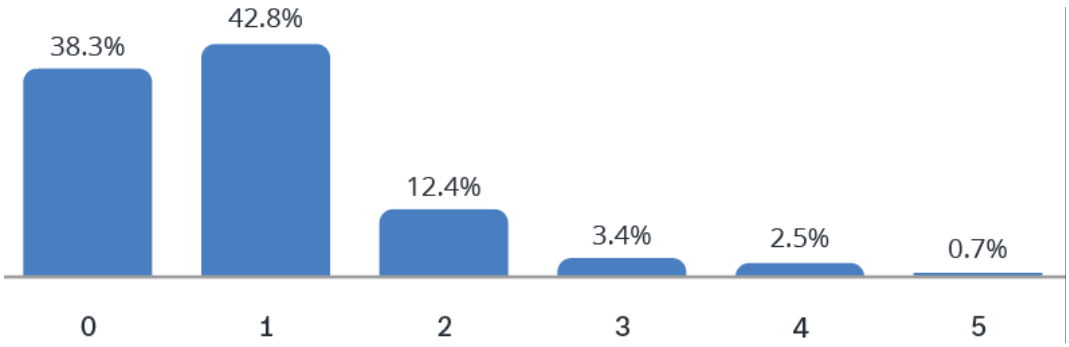


Canadian population data from Canada Census 2021 (source: https://www150.statcan.gc.ca/n1/daily-quotidien/220427/t002b-eng.htm)

- Number of family members in household, including self (n=445)



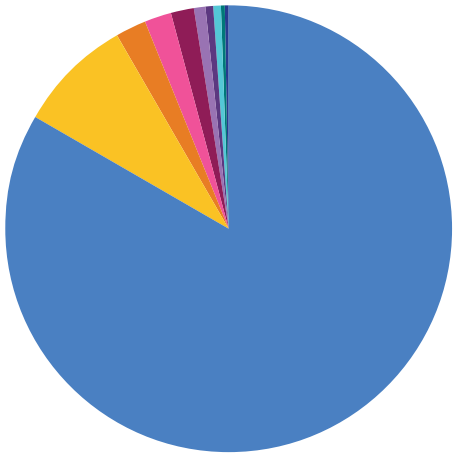
- Number of dependent family members* in household (n=444)



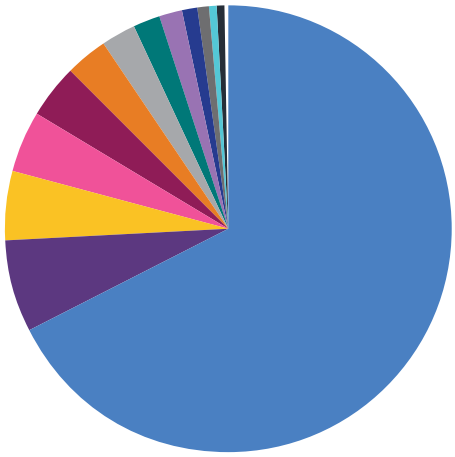
**Dependents were defined to include family members who are under 22 years old, or are 22 and older and can't financially support themselves due to a mental or physical condition.*

4.1 Autistic Adults

Racial-ethnic and Indigenous identification



Autistic Adults (n=439)



Canadian Population

	Autistic Adults	Canadian Population
Indigenous	8.4%	4.9%
First Nations	5.2%	2.9%
Métis	2.3%	1.7%
Inuk (Inuit)	0.2%	0.2%
Multiple Indigenous	0.7%	0.1%
White	83.6%	67.6%
South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.)	0.5%	6.9%
Mixed	2.1%	3.2%
Chinese	2.1%	4.5%
Black	1.6%	3.8%
Filipino	0.0%	2.5%
Arab	0.2%	1.9%
Latin American	0.9%	1.6%
Southeast Asian	0.0%	1.0%
West Asian	0.2%	1.0%
Korean	0.5%	0.6%
Japanese	0.0%	0.4%
Other	0.0%	0.2%

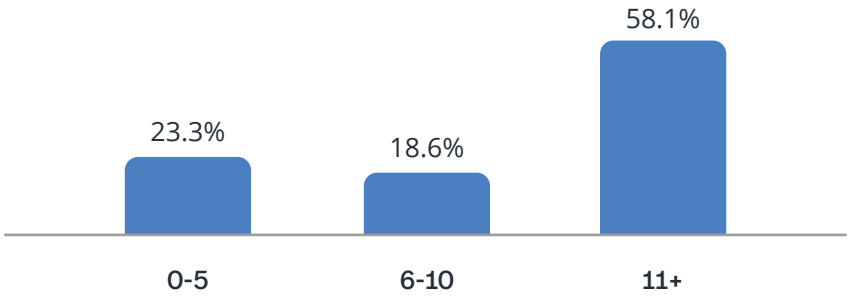
Canadian population data from Canada Census 2021. Source: https://www150.statcan.gc.ca/t1/tbl1/en/cv.action?pid=9810032401

- Among First Nations respondents (n=25), 68.0% reported living on-reserve

4.1 Autistic Adults

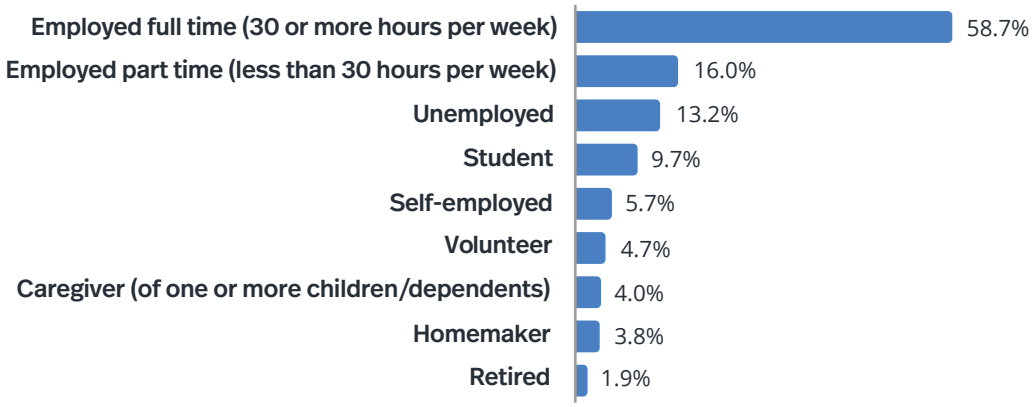
Newcomer status

- Of autistic adult respondents (n=448), 9.6% were not Canadian citizens by birth
- Years resided in Canada (for respondents who were not Canadian citizens by birth, n=43)

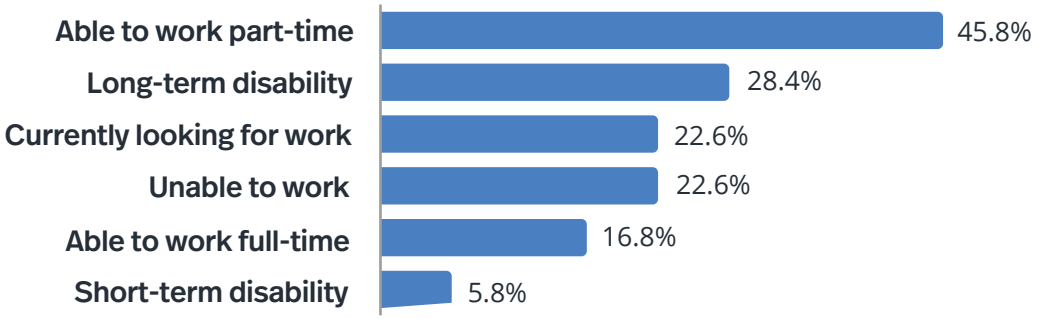


Occupational and economic status

- Current occupational status (multiple selections possible; n=424)

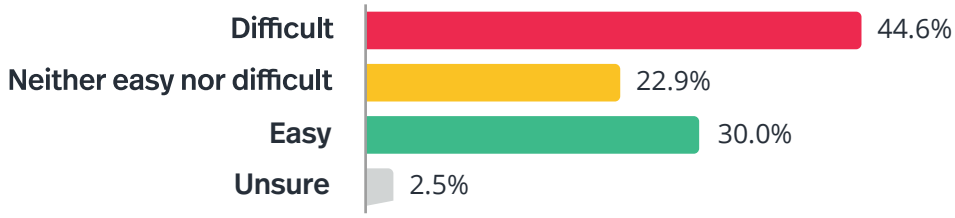


- Status among those not employed full time (multiple selections possible; n=190)



4.1 Autistic Adults

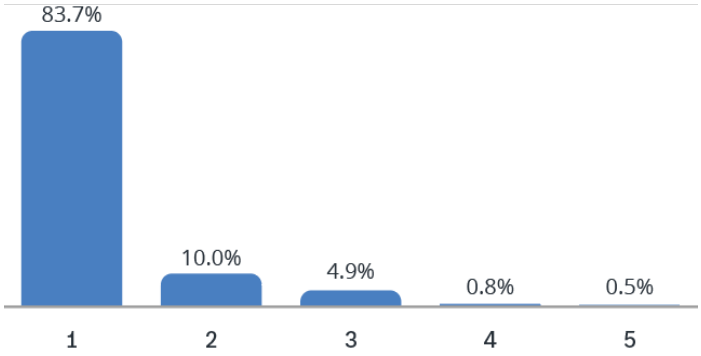
- Difficulty paying bills over the last year (n=437)



Autism diagnosis

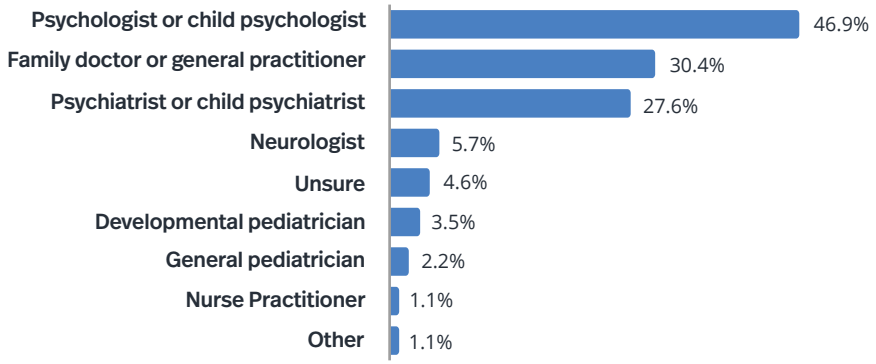
- Among autistic adult respondents (n=442), 84.2% reported having a formal diagnosis, while 15.8% self-identified as autistic
- Professionals diagnosing those with a formal diagnosis (n=369)

a. Number of professionals involved in diagnosis



b. Types of diagnosing professionals (multiple selections possible)

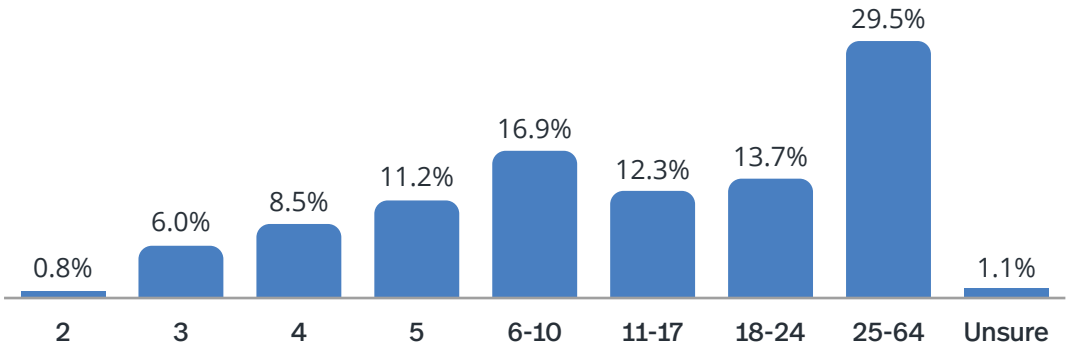
Note, the types of professionals who are considered qualified to participate in diagnostic assessments of autism varies across the different provinces and territories.



- Note, “Other” diagnosing professionals consisted primarily of speech and language pathologists, and some social workers.

4.1 Autistic Adults

- Age at diagnosis in years, among those formally diagnosed (n=366)

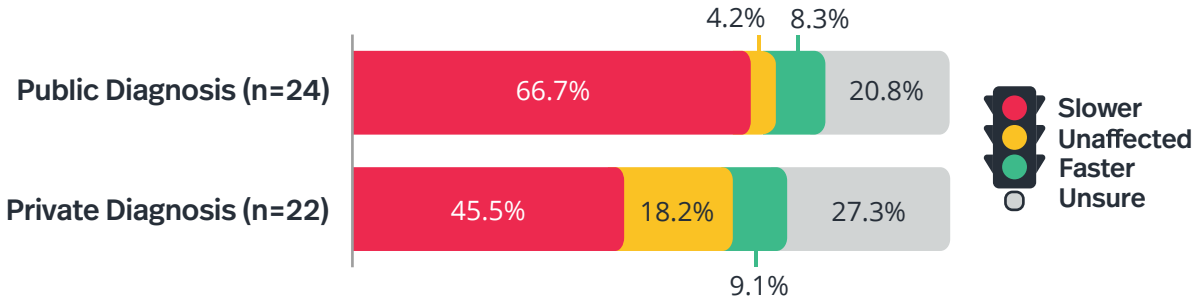


- 44% of undiagnosed (self-identified) respondents (n=61) reported they were currently seeking a diagnosis

4.1.b Effects of the COVID-19 pandemic on healthcare, disability- and autism-related services, supports and programs

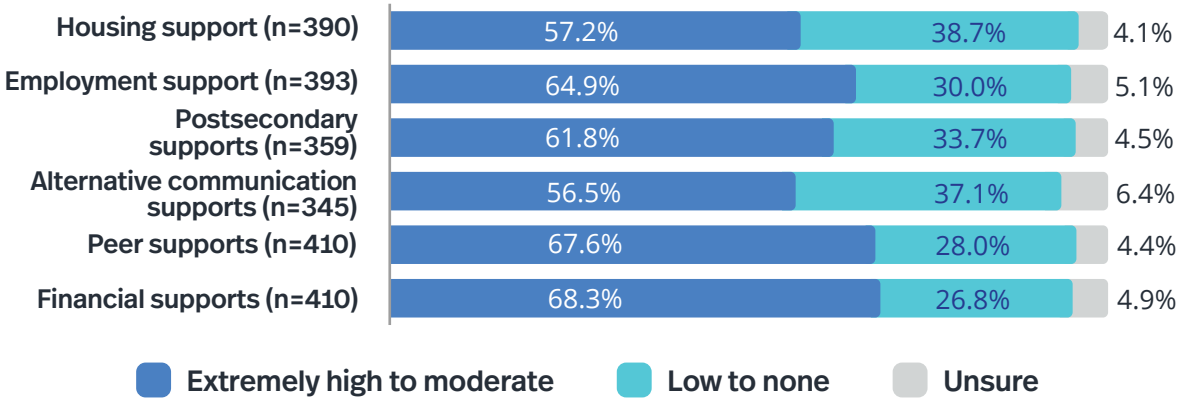
Disability- or Autism-related Supports and Programs

- Effect of COVID-19 pandemic on speed of obtaining a diagnosis (among adults currently seeking one)

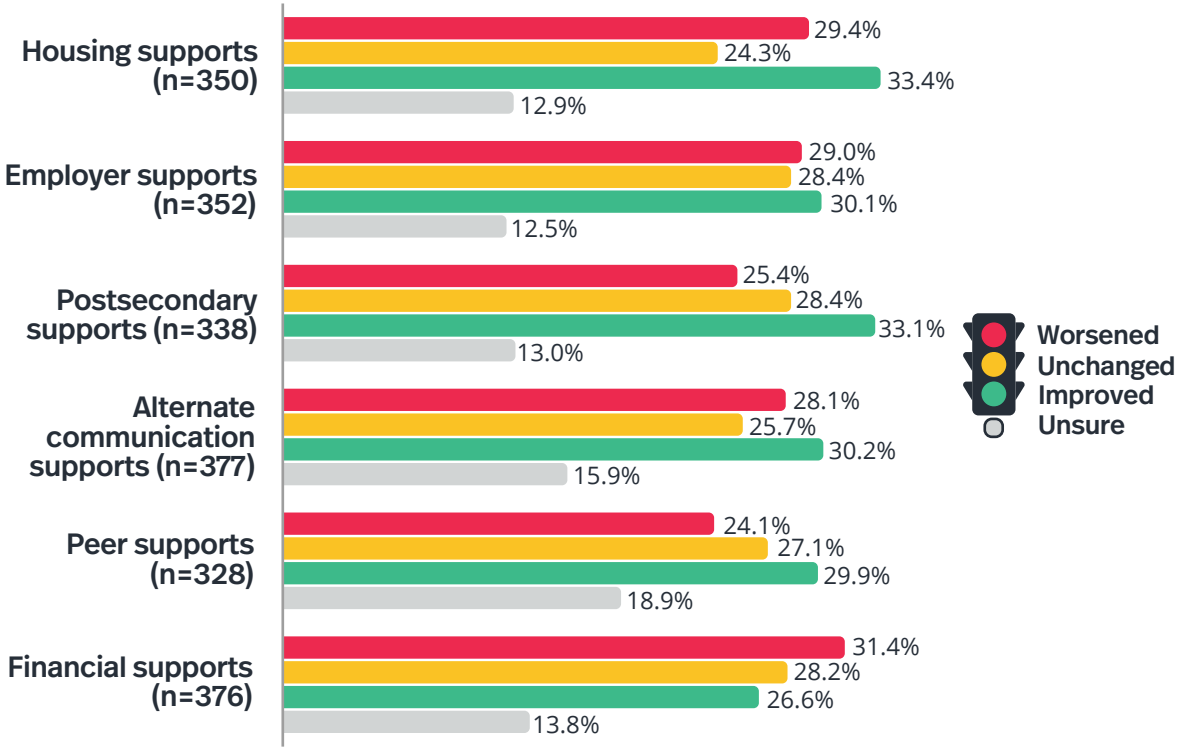


4.1 Autistic Adults

- Current level of unmet needs for disability- or autism-related supports and programs



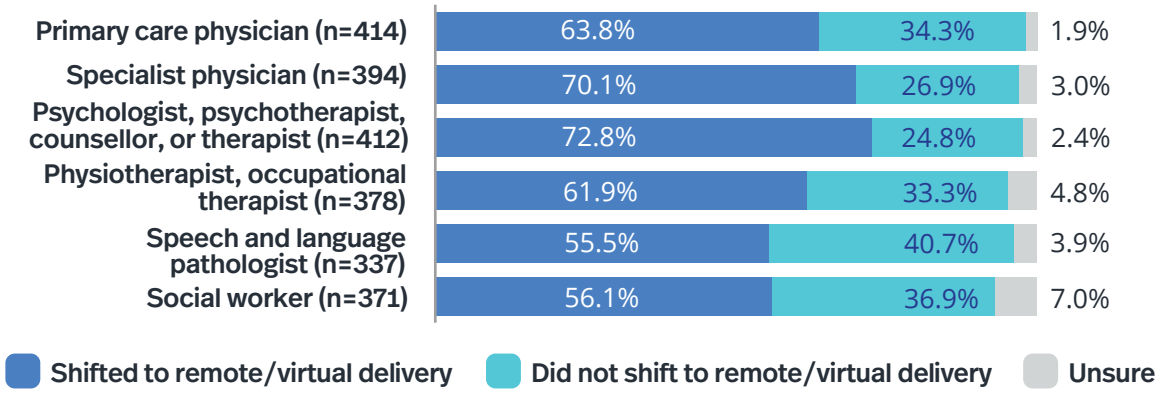
- Perceived change in access to disability- or autism-related supports and programs from before COVID-19 pandemic to now



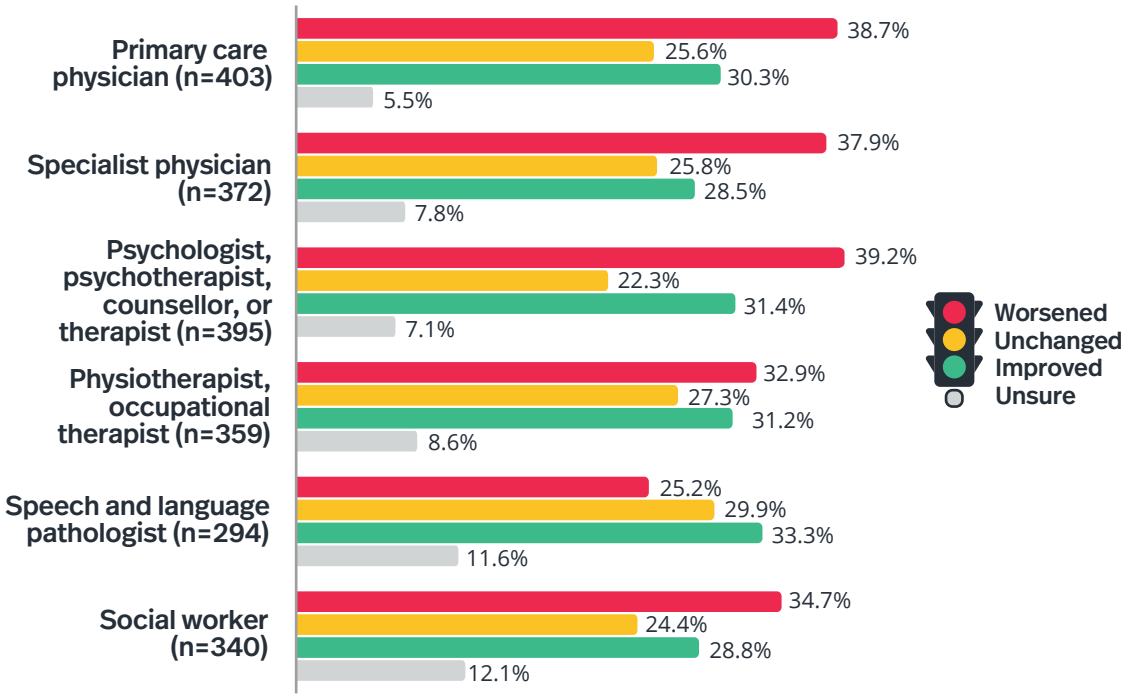
4.1 Autistic Adults

Health Professional Services

- Level of unmet needs for health professional services



- Perceived change in access to health professional services from before COVID-19 pandemic to now

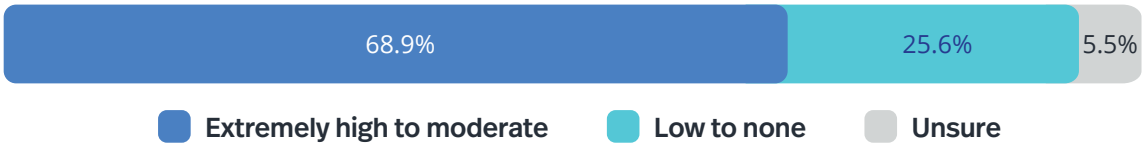


4.1 Autistic Adults

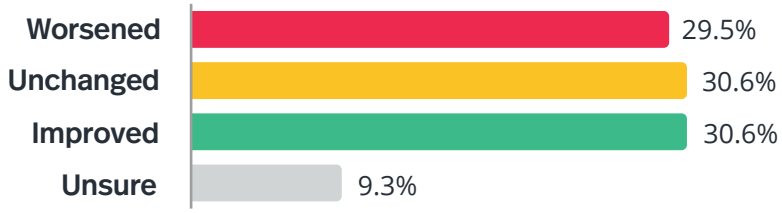
Supports to Help Navigate Care

- Level of unmet needs for supports to navigate care (n=399)

"Supports to navigate care" were defined to include services (e.g., telephone support from autism organization staff), information sources, and other resources that help guide respondents to the supports and services they need.

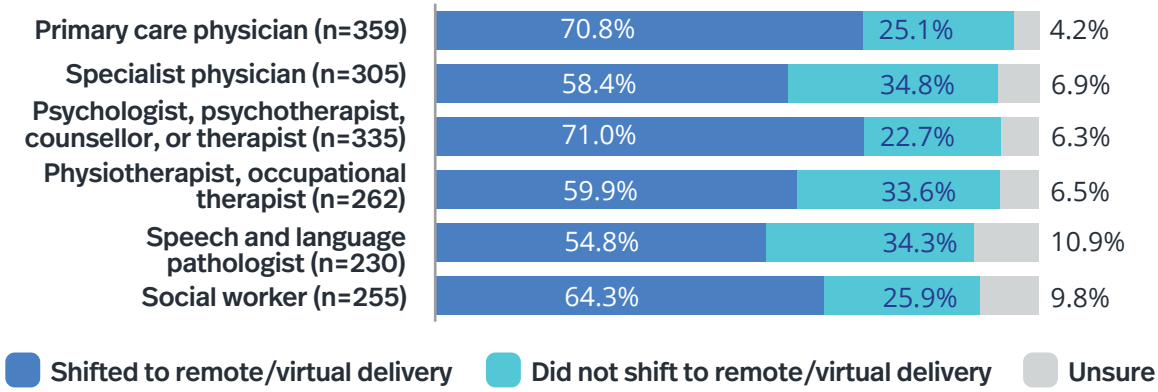


- Perceived change in access to supports to navigate care from before COVID-19 pandemic to now (n=386)



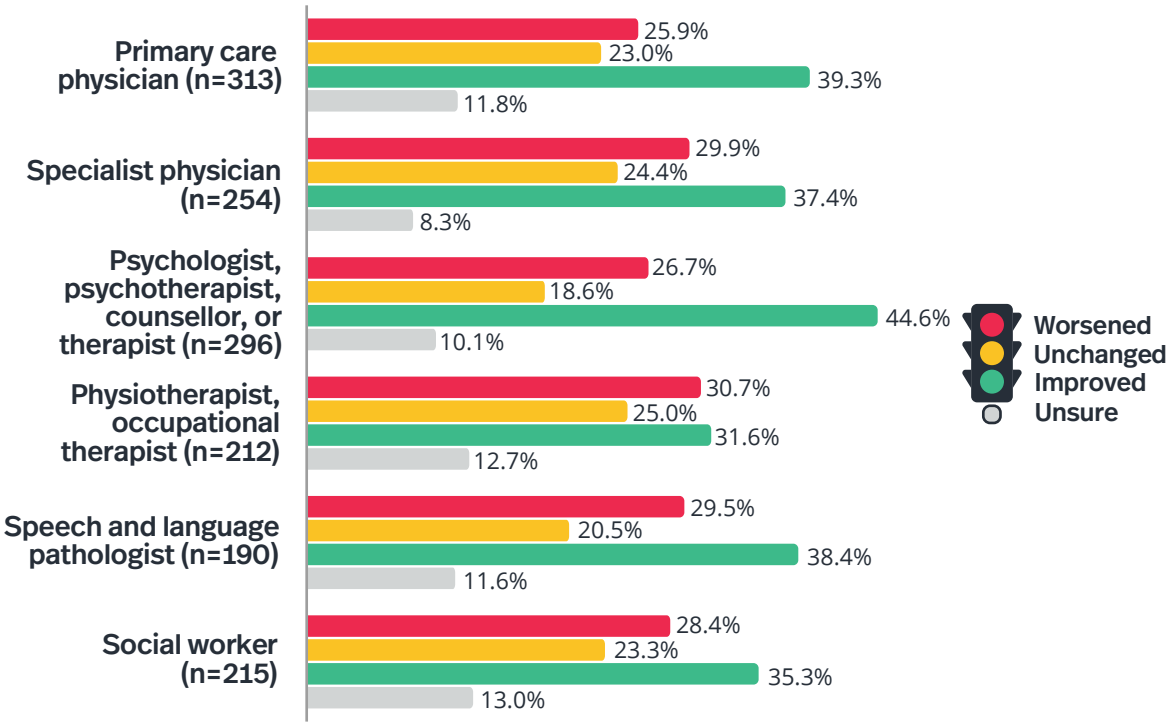
In-Person Versus Remote/Virtual Services and Supports

- Health professional services that shifted from in-person to remote during the COVID-19 pandemic

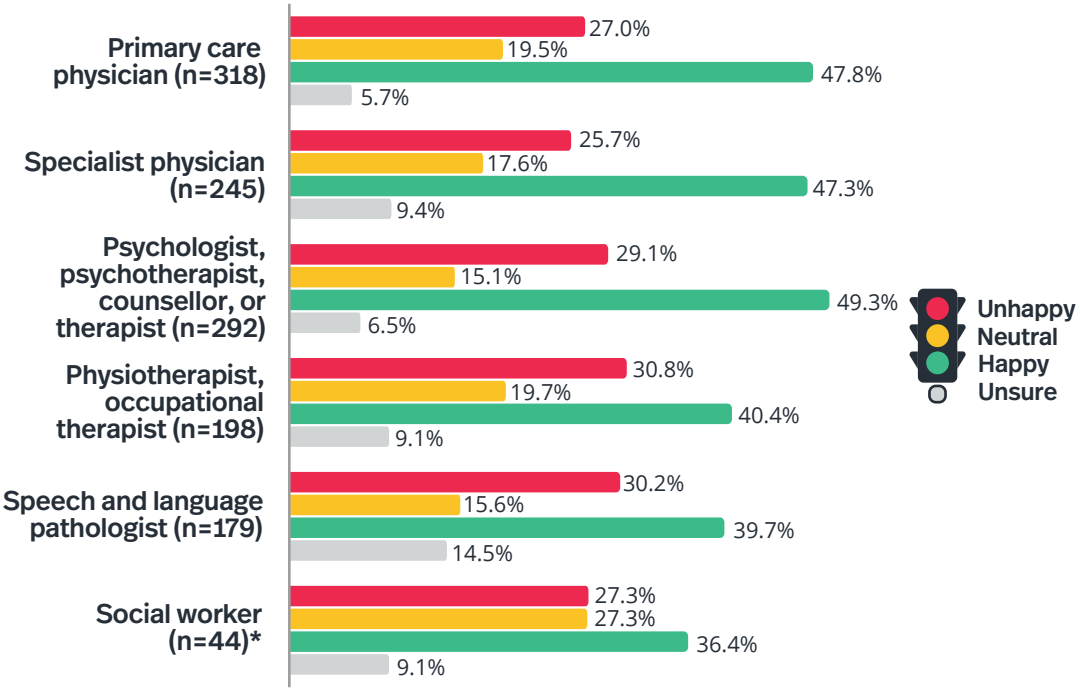


4.1 Autistic Adults

- Effect of shift to remote delivery of health professional services on accessibility



- Happiness with availability of health professional services via remote delivery



** "Social worker" was not displayed as an option until late in the suvrvey period, due to an error, resulting in fewer responses and a smaller sample size for this health professional type.*

4.1.c Impacts of the COVID-19 pandemic on the autistic adult respondent

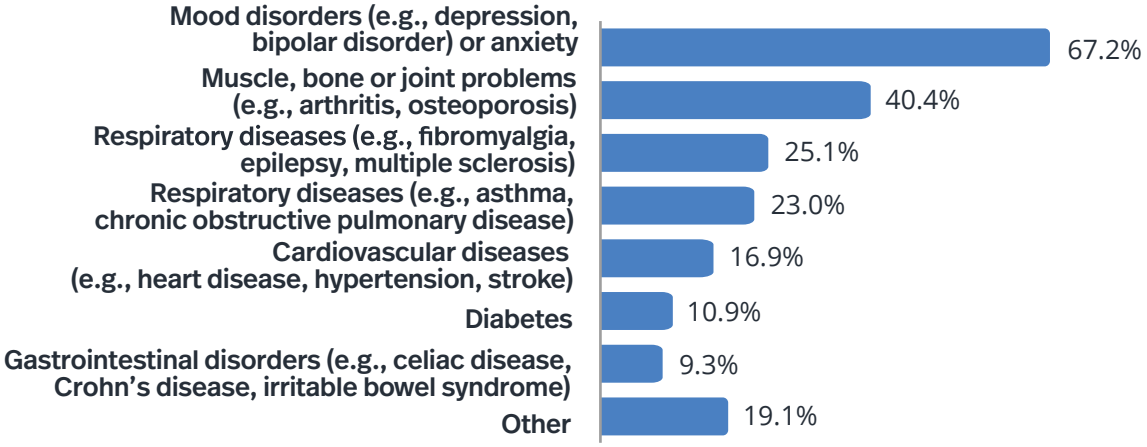
General health

- Change in general health from before the COVID-19 pandemic (n=382)

Long-term health conditions

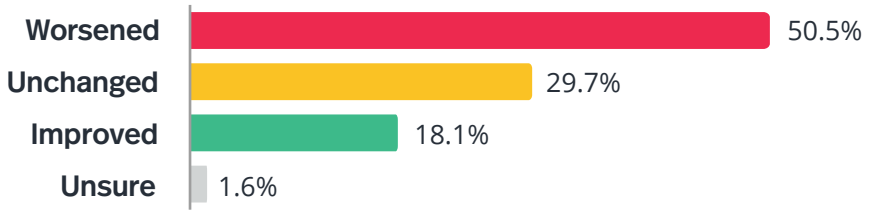
Long-term or chronic medical conditions were defined as conditions diagnosed by a health professional that "have lasted, or are expected to last, six months or more." Source: https://www23.statcan.gc.ca/imdb/p3Var.pl?Function=DEC&Id=82429. Respondents were asked to only consider conditions other than autism.

- Among autistic adult respondents (n=389), 44.2% reported the presence of long-term health conditions currently
- Types of long-term health conditions among respondents who reported having them (multiple selections possible; n=183)



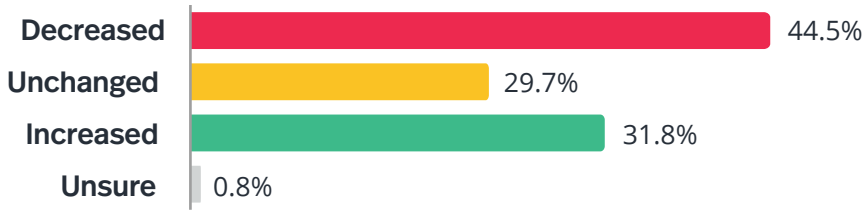
4.1 Autistic Adults

- Among those with long-term health conditions (n=184), 33.2% reported experiencing the onset of at least one long-term health condition since the COVID-19 pandemic (March 2020; this question did not ask about cause of onset).
- Changes in long-term health conditions (improvement or worsening) overall during pandemic to now (n=182)



Healthy habits (physical activity, sleep, eating habits)

- Change in level of daily physical activity from before the COVID-19 pandemic (n=380)



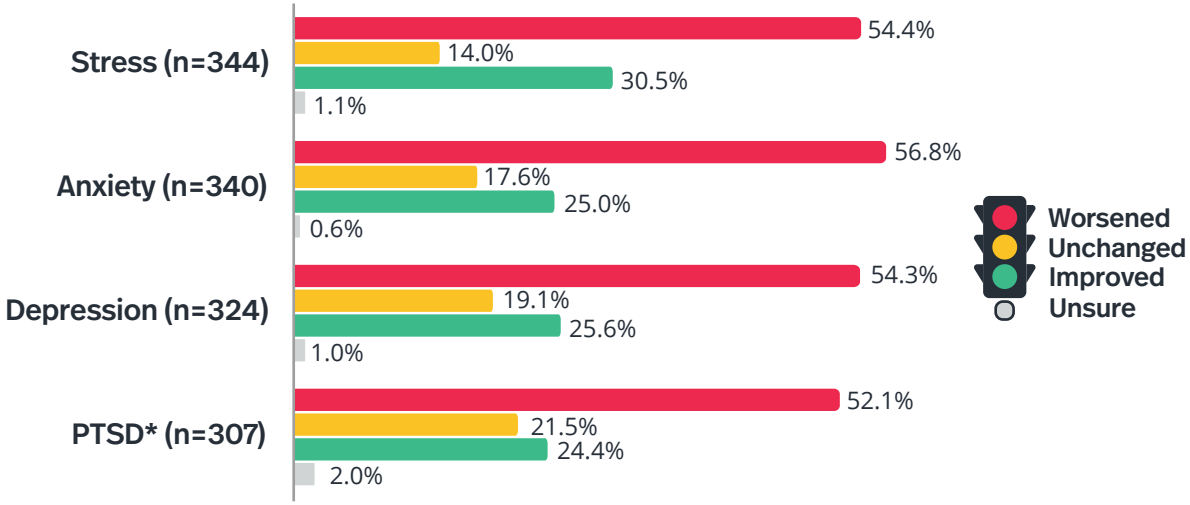
- Change in sleep habits from before the COVID-19 pandemic (n=382)

4.1 Autistic Adults

- Change in eating habits from before the COVID-19 pandemic (n=380)

Mental health (stress, anxiety, depression, ability to cope)

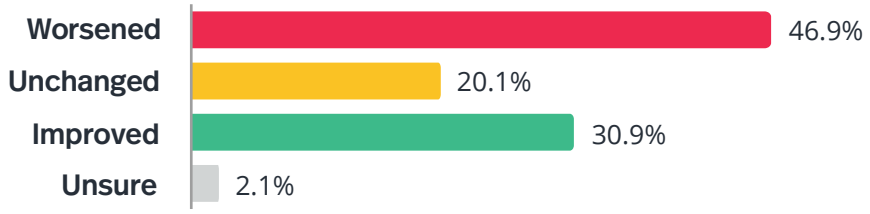
- Change in mental health from before the COVID-19 pandemic



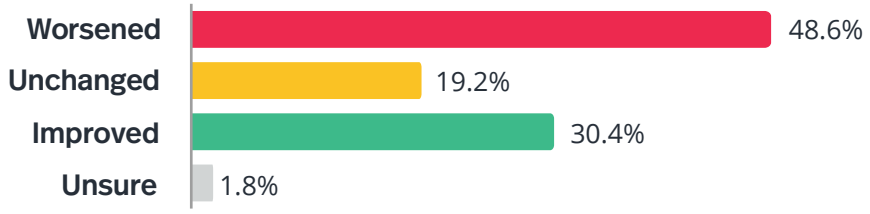
** Respondents were asked to report on post-traumatic stress disorder, or symptoms from past experiences of traumatic events.*

4.1 Autistic Adults

- Change in ability to regulate emotions from before the COVID-19 pandemic (n=388)

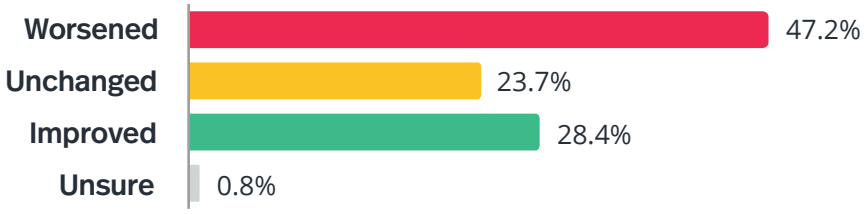


- Changes in frequency of meltdowns or shutdowns from before the COVID-19 pandemic (n=385)



Mental focus and concentration

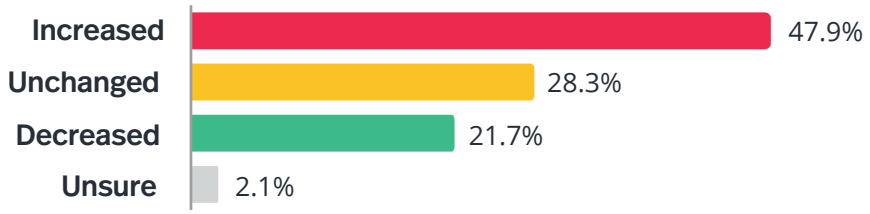
- Change in ability to mentally focus or concentrate from before the COVID-19 pandemic (n=388)



4.1 Autistic Adults

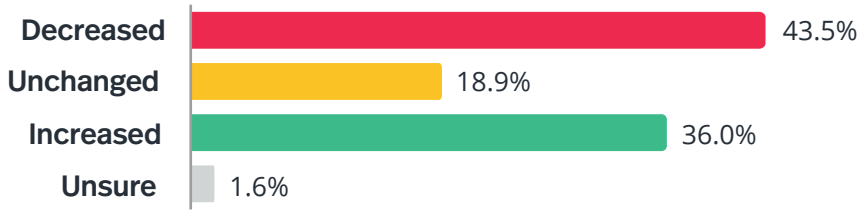
Daily life experiences and habits (repetitive habits, special interests, burnout)

- Change in repetitive habits (including self-stimulation or stimming, echolalia or repeating others' words, sniffing, etc.) from before the COVID-19 pandemic (n=374)



- Change in engagement in special interests (including hobbies, sports, or other extracurricular activities) from before the COVID-19 pandemic (n=385)

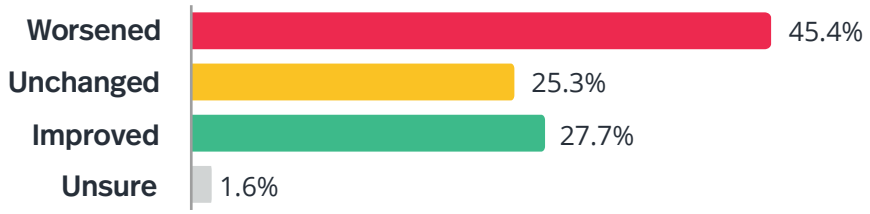
- Change in ability to manage or avoid burnout (state of emotional, physical, and mental exhaustion; can include autistic burnout) from before the COVID-19 pandemic (n=375)



4.1 Autistic Adults

Important relationships (friends, family, significant others)

- Impact of the COVID-19 pandemic (including because of closures, restrictions, policies or other pandemic-related changes) on quality of important relationships (friends, family, or significant others) (n=379)



Social life

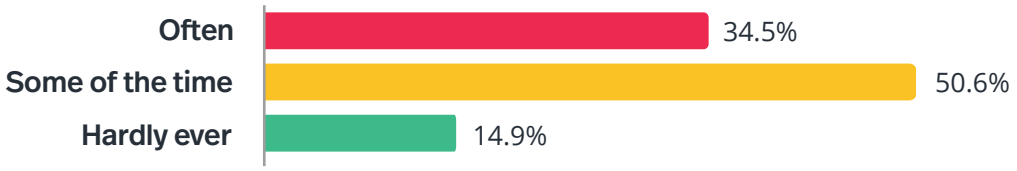
- Change in level of satisfaction with personal social life from before the COVID-19 pandemic (n=372)

4.1 Autistic Adults

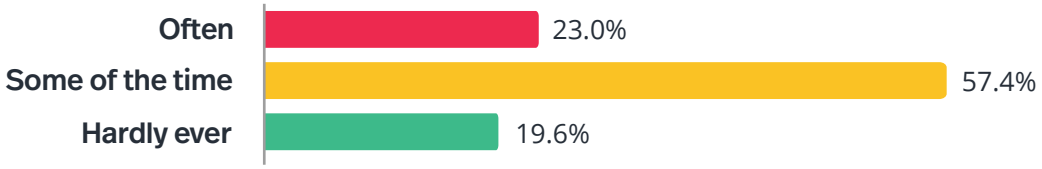
Loneliness

- Loneliness: How often do you feel that you lack companionship?

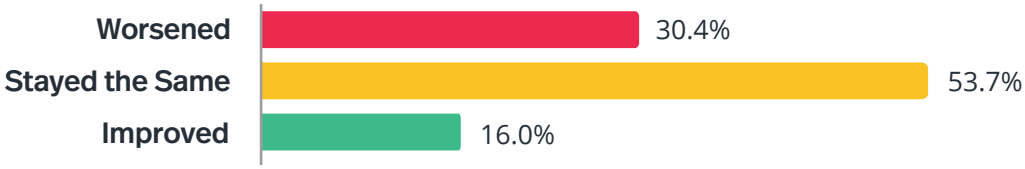
a) Currently (n=328)



b) Before the COVID-19 pandemic (n=323)



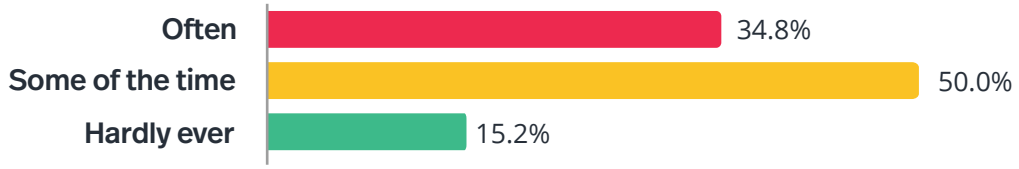
c) Change in frequency of feeling lack of companionship from before the COVID-19 pandemic to now (n=326)



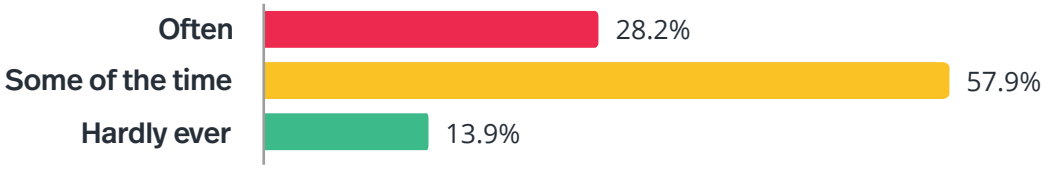
4.1 Autistic Adults

- Loneliness: How often do you feel left out?

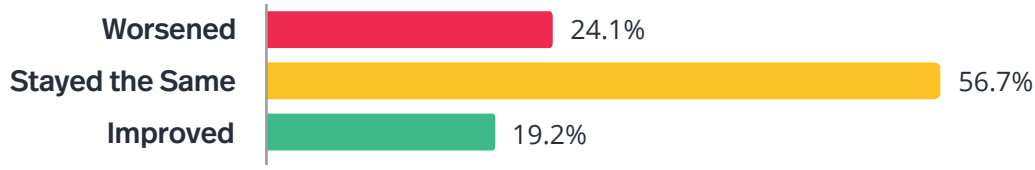
a) Currently (n=328)



b) Before the COVID-19 pandemic (n=323)



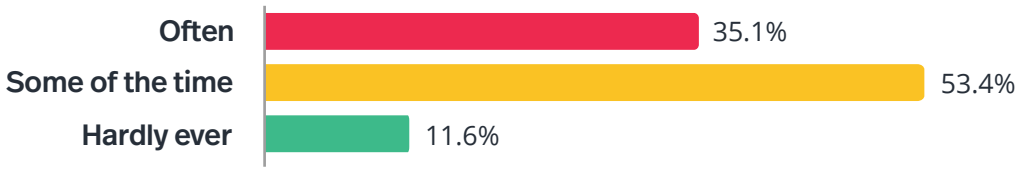
c) Change in frequency of feeling left out from before the COVID-19 pandemic to now (n=323)



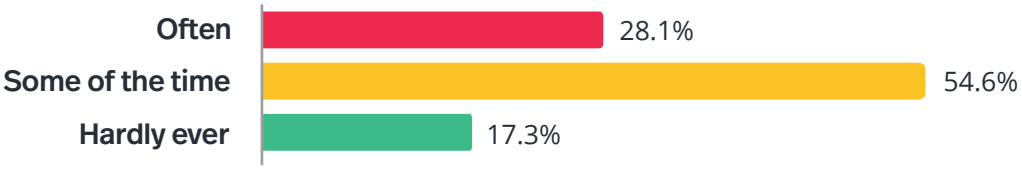
4.1 Autistic Adults

- Loneliness: How often do you feel isolated from others?

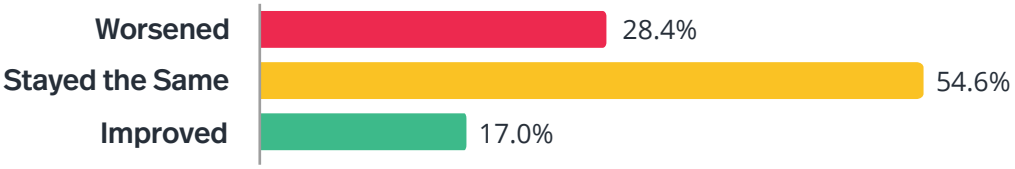
a) Currently (n=328)



b) Before the COVID-19 pandemic (n=324)



c) Change in frequency of feeling isolated from others from before the COVID-19 pandemic to now (n=324)



The questions above about loneliness were adapted from the UCLA 3-item Loneliness Scale. Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT. A Short Scale for Measuring Loneliness in Large Surveys: Results From Two Population-Based Studies. Res Aging. 2004;26(6):655-672. doi: 10.1177/0164027504268574. PMID: 18504506; PMCID: PMC2394670.

4.1 Autistic Adults

Postsecondary education and employment

- Of autistic adult respondents (n=380), 23.9% reported being enrolled in a post-secondary education program during the COVID-19 pandemic (i.e., from March 2020 to survey completion fall 2023)
- Of those who reported being enrolled in postsecondary education (n=91), 39.6% reported interrupting their enrollment at some point due to the COVID-19 pandemic
- Of those who reported interrupting enrollment in postsecondary education due to the COVID-19 pandemic (n=36), 72.2% reported NOT resuming enrollment

- Of autistic adult respondents (n=378), 74.9% reported being employed at some point during the COVID-19 pandemic (i.e., from March 2020 to survey completion fall 2023)
- Change in level of employment from before the COVID-19 pandemic (n=279)

- Of those who reported being employed (n=282), 71.6% reported fully interrupting their employment at some point due to COVID-19 pandemic
- Of those who reported interrupting their employment (n=201), 6.0% reported NOT resuming employment

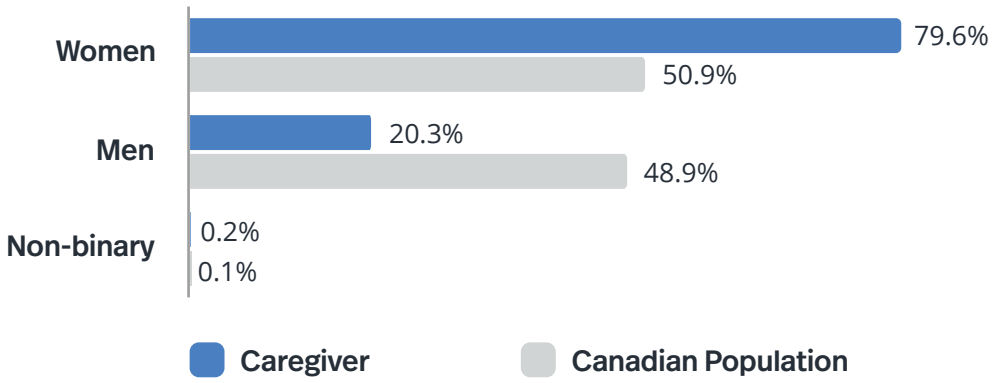
- Change in income (from all sources) from before the COVID-19 pandemic (n=366)

4.2 Caregivers

4.2.a About the Caregivers Who Responded

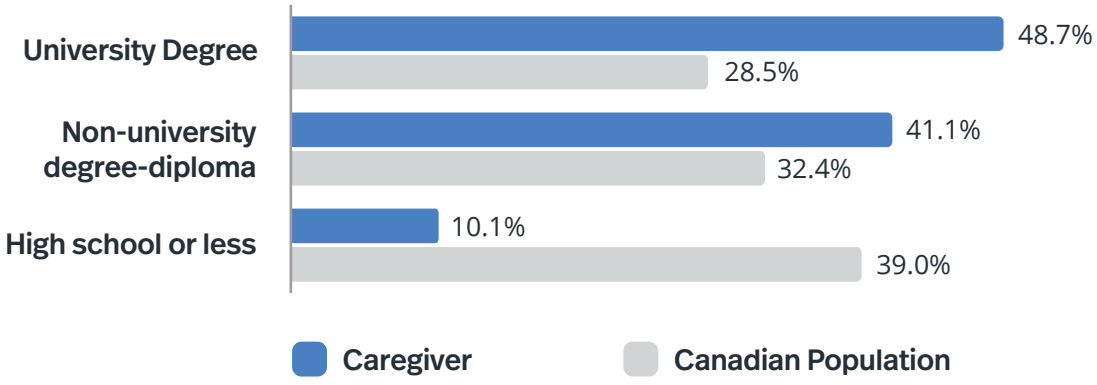
Basic demographics

- Gender (n=1,076)



Canadian population data from Canada Census 2021 (source: https://www150.statcan.gc.ca/n1/daily-quotidien/220427/t002b-eng.htm)

- Education Level (n=1,075)

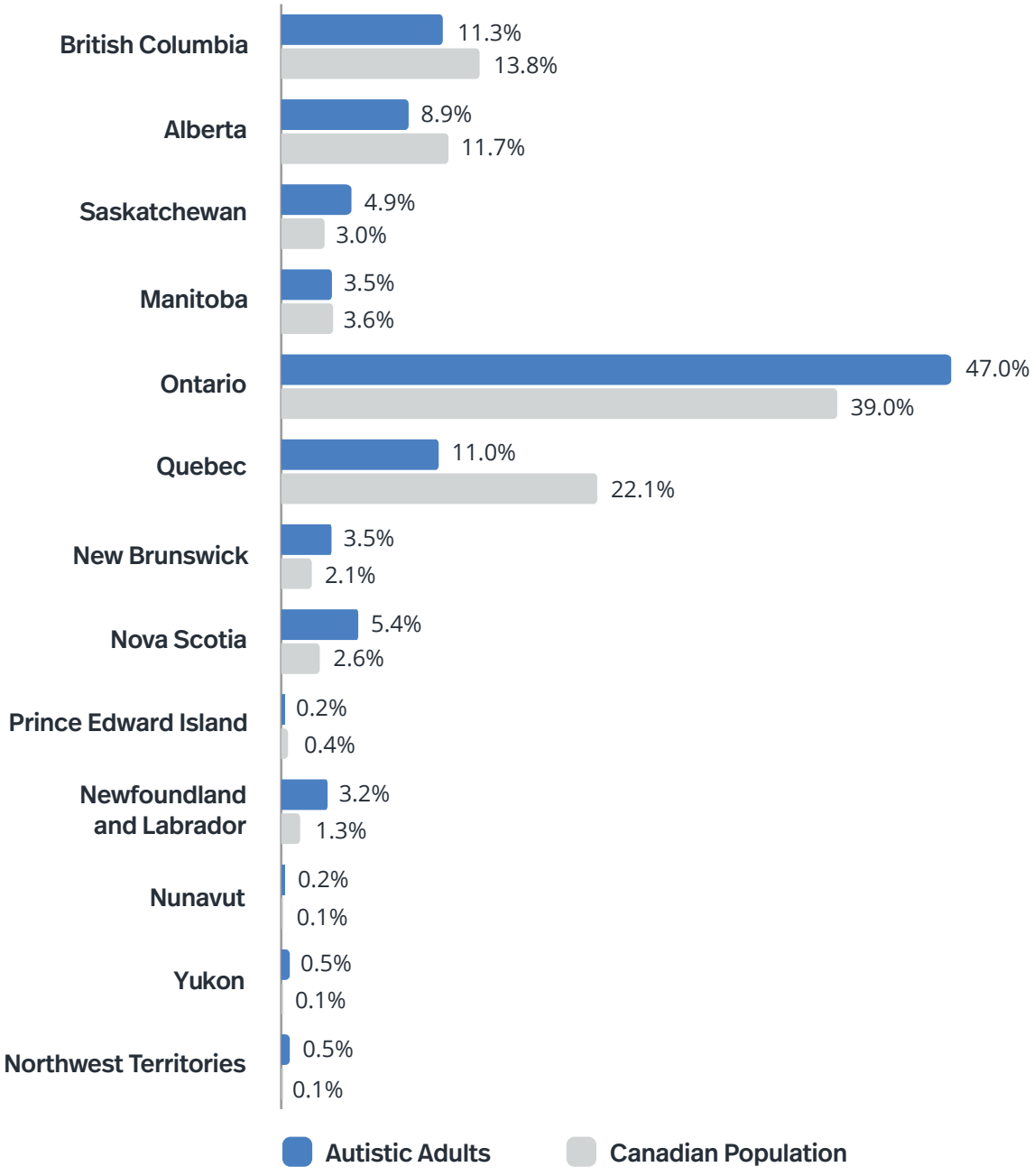


**"Non-university degree or diploma," includes those reporting having completed college, CEGEP or other non-university certificates or diplomas, or some college or university. Canadian population data from 2021 Canadian Census. Source: https://www150.statcan.gc.ca/t1/tbl1/en/cv!recreate.action?pid=9810042901&selectedNodeIds=4D4,4D5,4D13,8D1&checkedLevels=0D1,1D1,2D1,4D1,5D1,6D1,6D2,6D3,6D4&refPeriods=20210101,20210101&dimensionLayouts=layout2,layout2,layout2,layout2,layout2,layout2,layout3,layout2,layout2&vectorDisplay=false*

4.2 Caregivers

Geography and Language

- Province/Territory of residence (n=1,073)



Canadian population data from Canada's population estimates, third quarter 2023, Statistics Canada. Source: https://www150.statcan.gc.ca/n1/daily-quotidien/231219/dq231219c-eng.htm

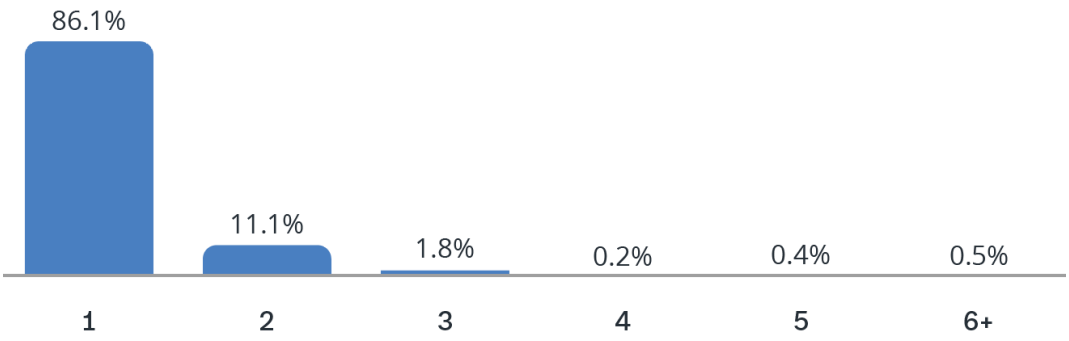
4.2 Caregivers

- Of respondents (n=1,066), 13.0% live in a wide-area rual region*

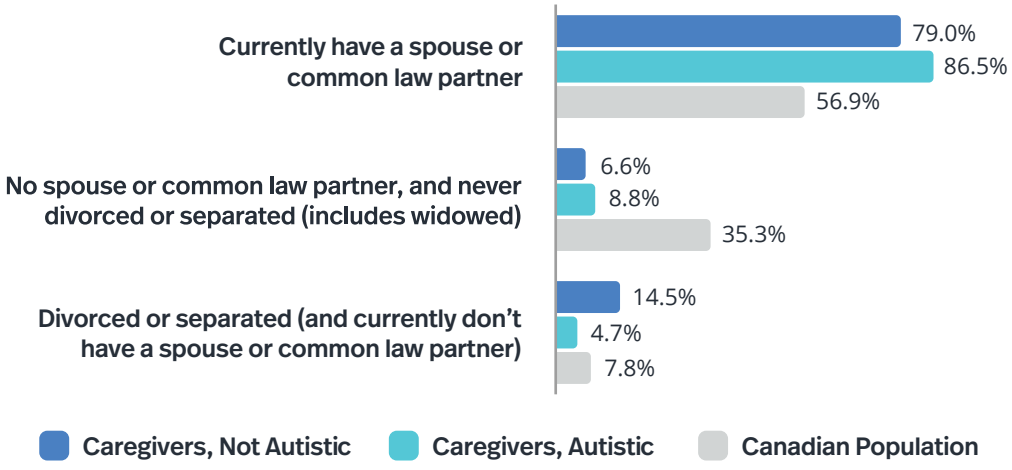
- Languages most often used at home (n=1,081)
  - English 87.1%
  - French 6.8%
  - Other Languages 4.9%
  - American Sign Language 1.0%
  - A First Nations Language 0.2%

Family structure and caregiving situation

- Number of autistic children (of any age) under care (n=1,047)



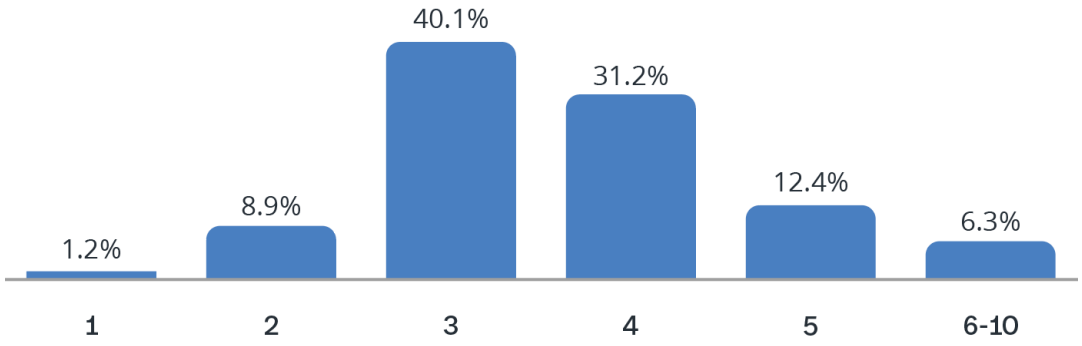
- Marital status** (n=1,063)



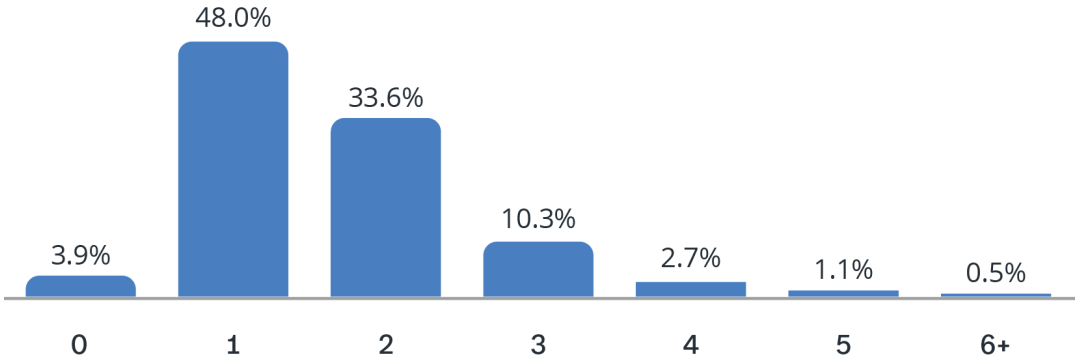
**Wide-area rural region is based on the second digit of the postal code and provides only a rough estimate of rurality. There was not enough information to differentiate whether people lived in urban or suburban areas.*
*** Canadian population data from Canada Census 2021 (source: https://www150.statcan.gc.ca/n1/daily-quotidien/220427/t002b-eng.htm)*

4.2 Caregivers

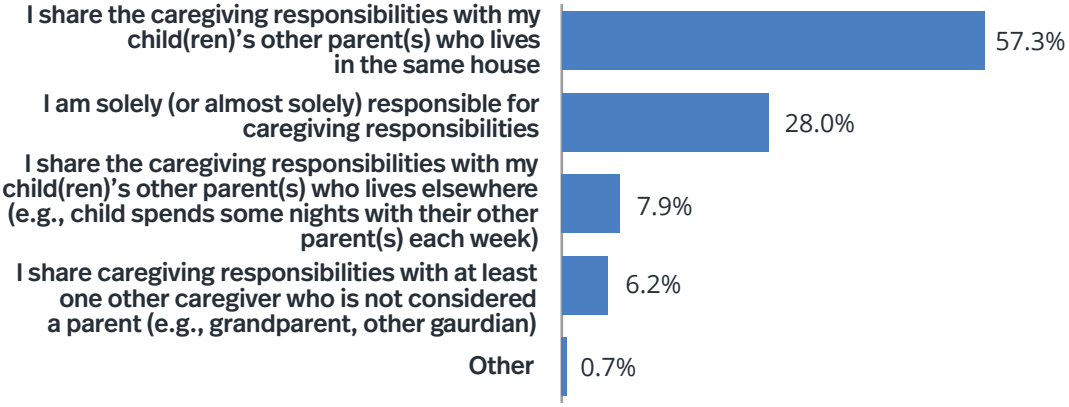
- Number of family members in household, including partners and self (n=1,081)



- Dependent family members* in household (n=1,081)



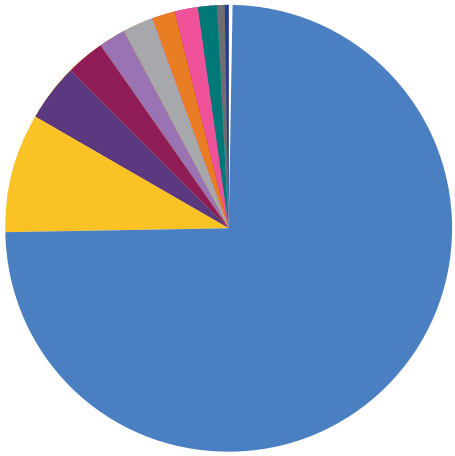
- Caregiving situation (n=1,044)



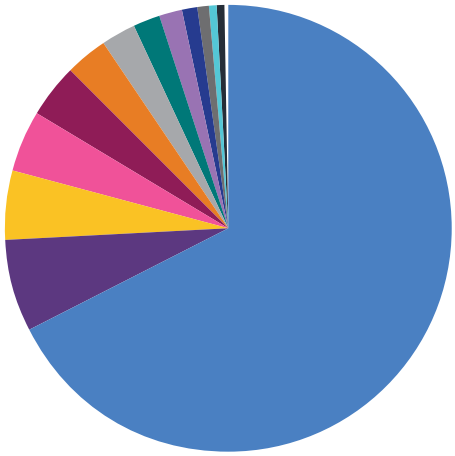
**Dependents were defined to include family members who are under 22 years old, or are 22 and older and can't financially support themselves due to a mental or physical condition.*

4.2 Caregivers

Racial-ethnic and Indigenous identification



Caregiver (n=1,040)



Canadian Population

	Caregivers	Canadian Population
Indigenous	8.7%	4.9%
First Nations	6.7%	2.9%
Métis	1.6%	1.7%
Inuk (Inuit)	0.1%	0.2%
Multiple Indigenous	0.3%	0.1%
White	74.8%	64.6%
South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.)	4.0%	6.9%
Mixed	1.8%	3.2%
Chinese	1.6%	4.5%
Black	2.8%	3.8%
Filipino	2.0%	2.5%
Arab	1.4%	1.9%
Latin American	2.1%	1.6%
Southeast Asian	0.5%	1.0%
West Asian	0.1%	1.0%
Korean	0.0%	0.6%
Japanese	0.1%	0.2%
Other	0.0%	0.4%

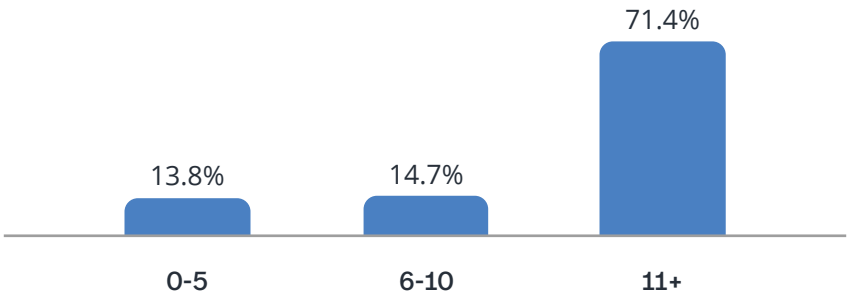
Canadian population data from Canada Census 2021. Source: https://www150.statcan.gc.ca/t1/tbl1/en/cv.action?pid=9810032401

4.2 Caregivers

- Among First Nations respondents (n=71), 66.2% reported living on-reserve

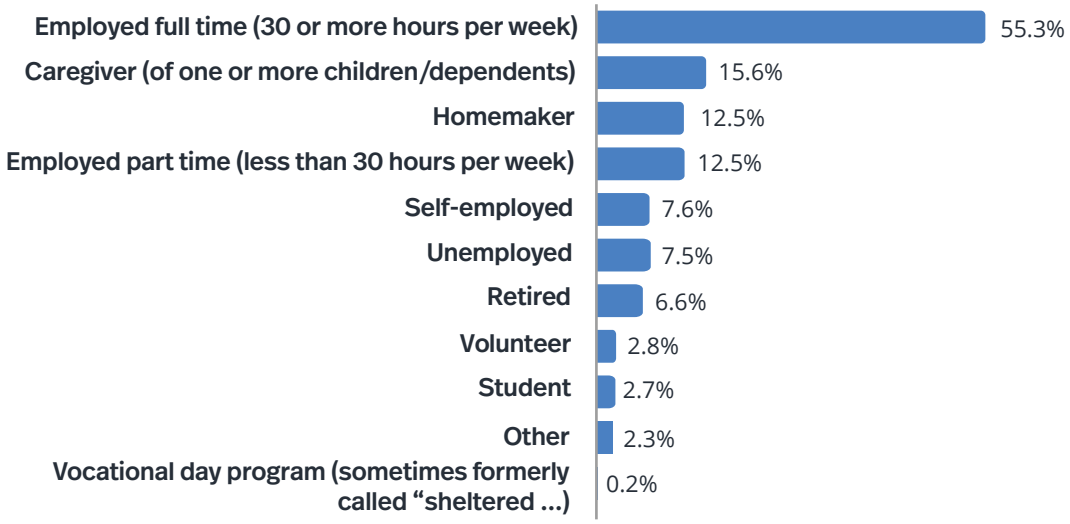
Newcomer status

- Among caregiver respondents (n=1,082), 20.5% were not Canadian citizens by birth
- Years residing in Canada (for respondents who were not Canadian citizens by birth, n=224)



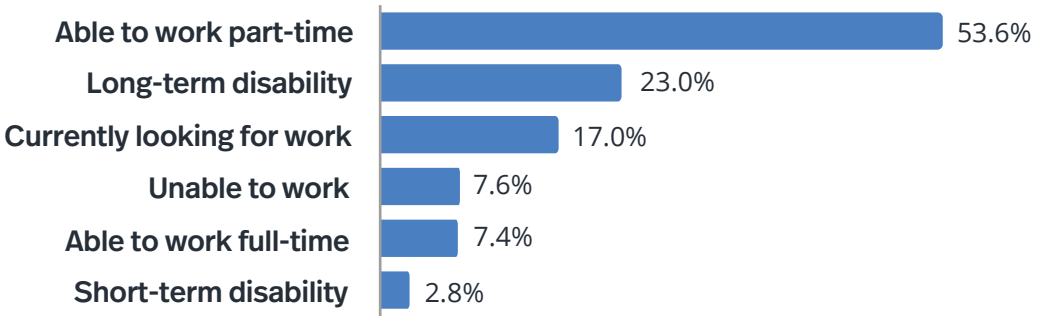
Occupational and economic status

- Occupational status (multiple selections possible; n=1,068)

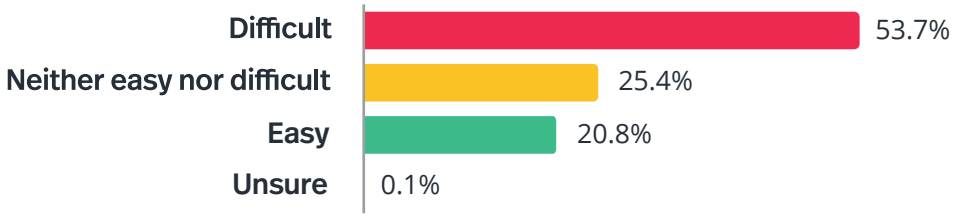


4.2 Caregivers

- Status if not employed full time (multiple selections possible, n=860)

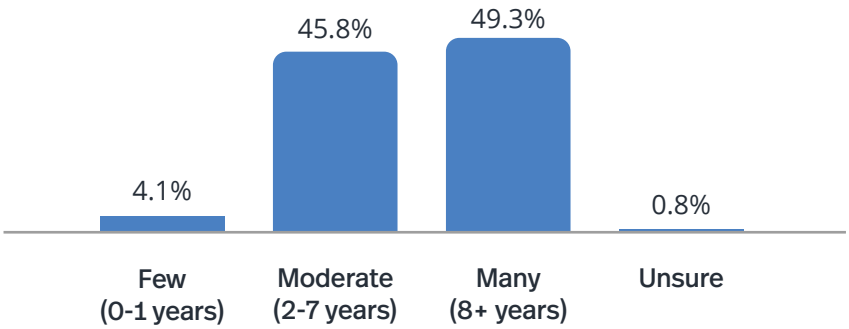


- Difficulty paying bills over the last year (n=1,062)



Experience navigating autism-related care

- Years caregivers' had spent navigating autism-related care (n=1,050)



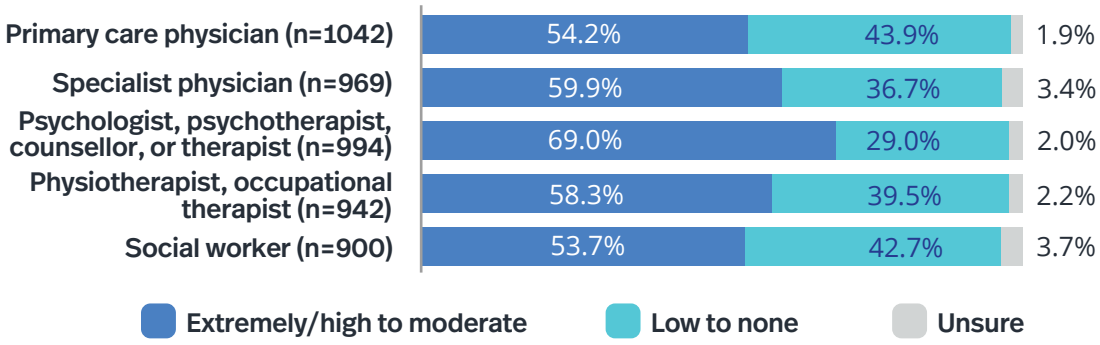
- Caregivers (n=1,082) reported spending an average of 18.6 hours per week navigating and supporting autism-related care for their child(ren)

4.2 Caregivers

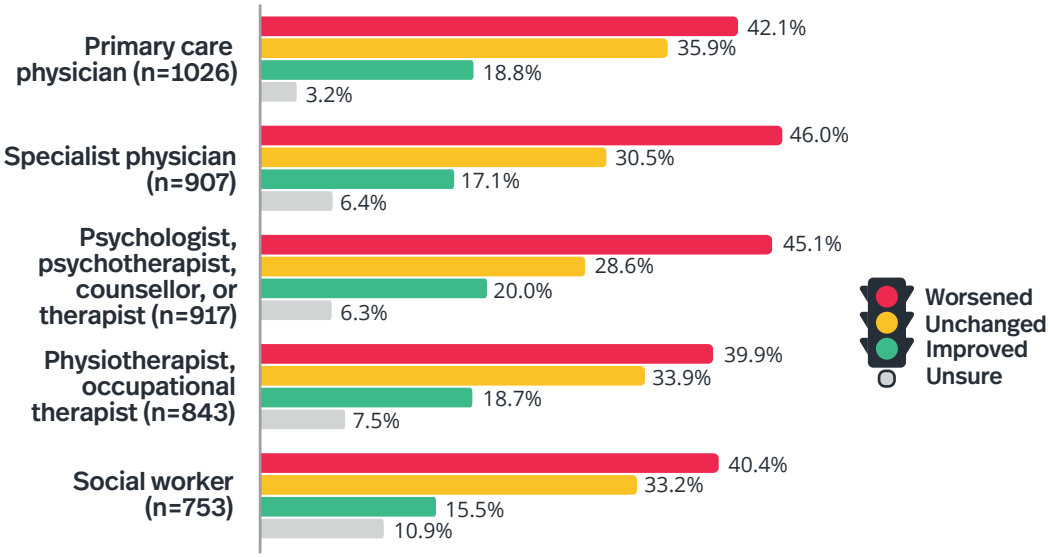
4.2.b Effects of the COVID-19 pandemic on services and supports for the caregiver

Healthcare services for the caregiver

- Level of caregiver's unmet needs for health professional services



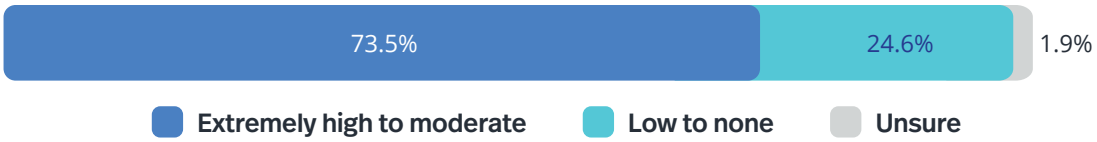
- Perceived change in access to caregiver-focused health professional services from before COVID-19 pandemic to now



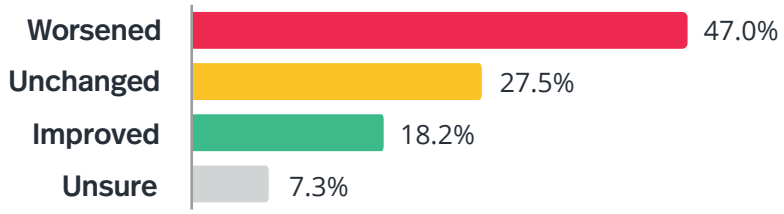
4.2 Caregivers

Supports to navigate care for autistic child(ren)

- Current level of unmet needs for care navigation supports (n=989)

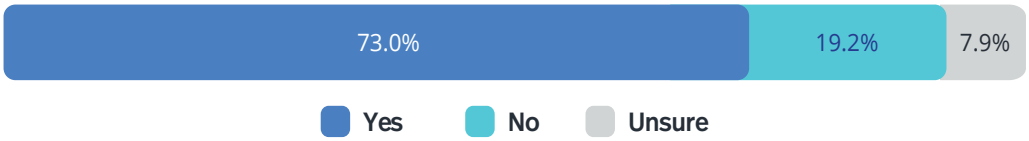


- Perceived change in access to care navigation supports from before COVID-19 pandemic to now (n=954)

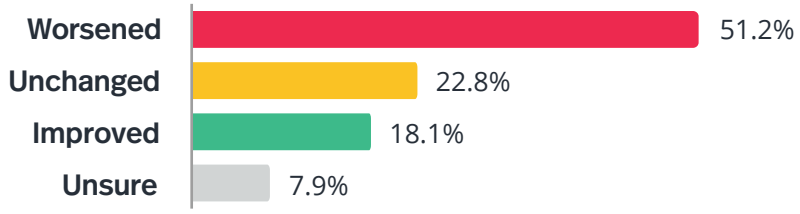


Respite

- Increase in need for respite care at some point because of COVID-19 pandemic (n=777)



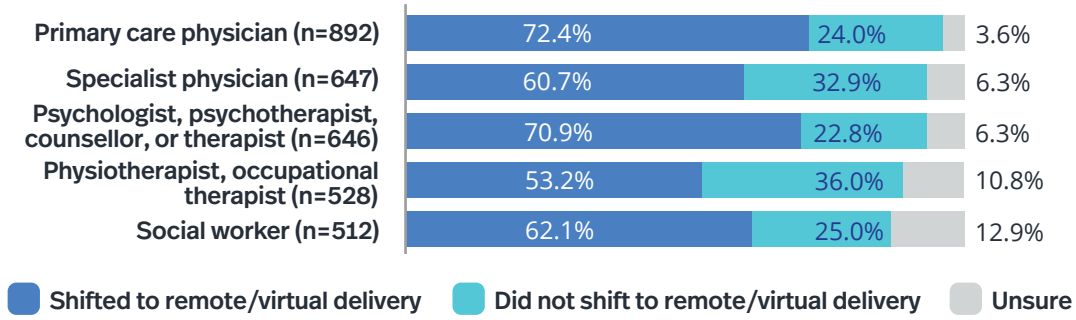
- Perceived change in access to respite care from before COVID-19 pandemic to now (n=758)



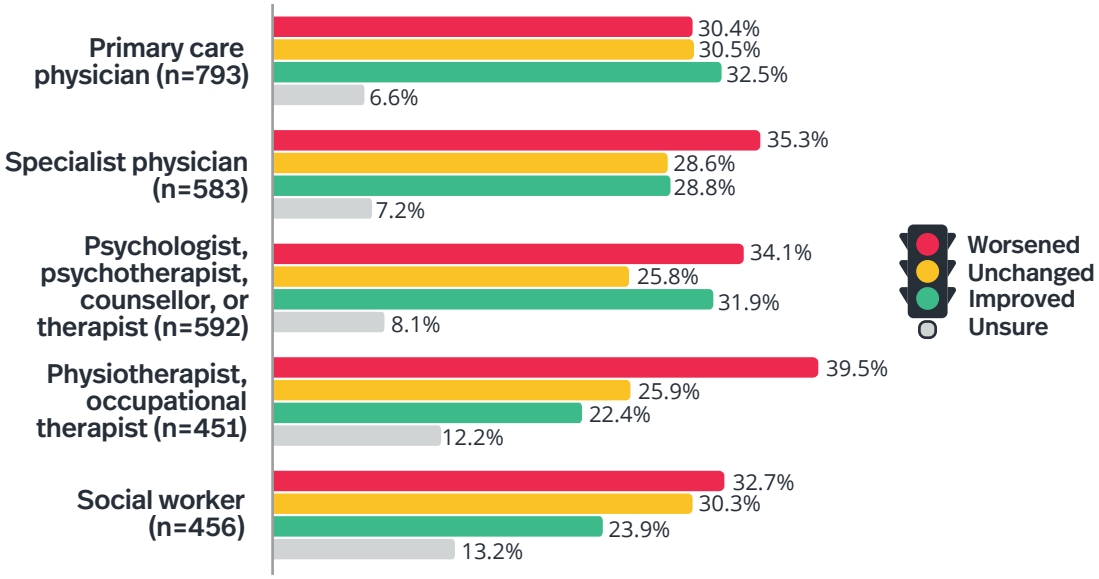
4.2 Caregivers

In-person vs. remote services and supports for the caregiver

- Caregiver-focused health professional services that shifted from in-person to remote at some point during the COVID-19 pandemic

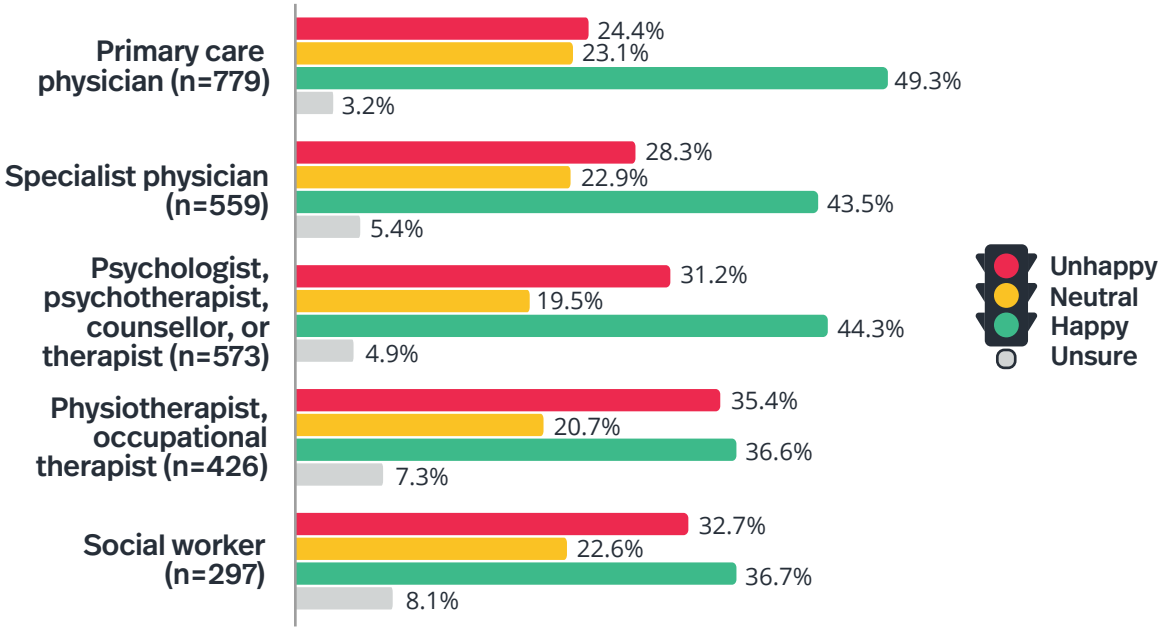


- Effect of shift to remote delivery of caregiver-focused health professional services on their accessibility



4.2 Caregivers

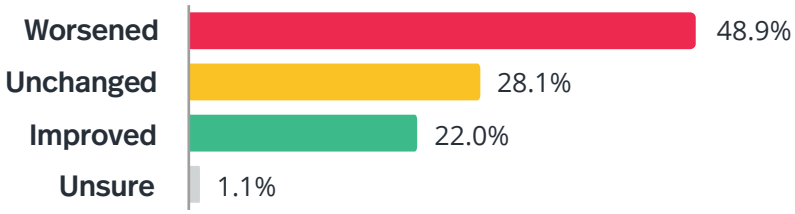
- Happiness with availability of caregiver-focused health professional services via remote delivery



4.2.c Impacts of the COVID-19 pandemic on the caregiver

Caregiver general health

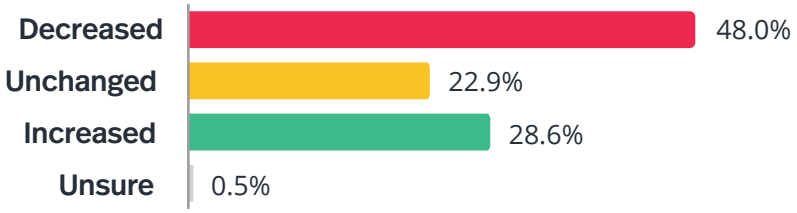
- Change in general health from before the COVID-19 pandemic (n=933)



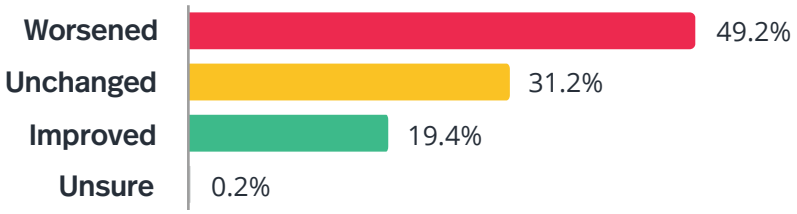
4.2 Caregivers

Healthy habits (physical activity, sleep, eating habits)

- Change in level of daily physical activity from before the COVID-19 pandemic (n=931)



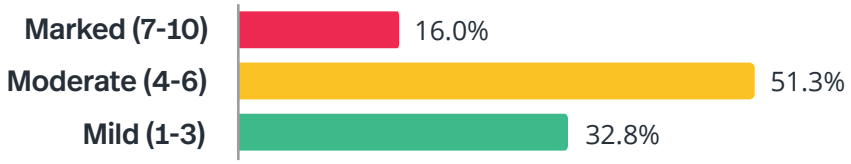
- Change in sleep habits from before the COVID-19 pandemic (n=933)



- Change in eating habits from before the COVID-19 pandemic (n=935)

Family distress and caregiver mental health

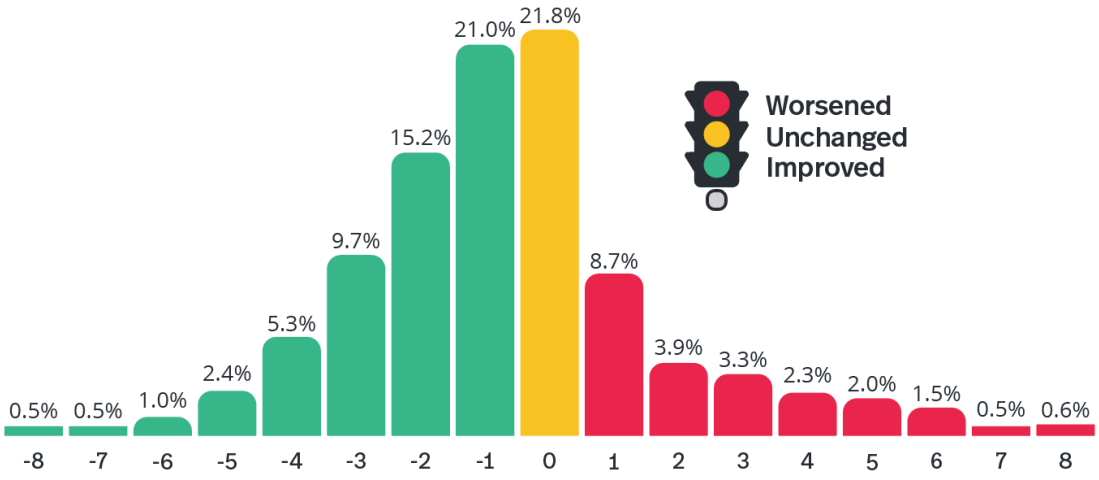
- Level of family distress currently (n=800)



4.2 Caregivers

- Level of family distress at the most stressful part of the COVID-19 pandemic (n=797)

- Level of family distress improved from the most stressful part of the COVID-19 pandemic for 55.5% of respondents, and worsened for 22.7% of respondents (n=797; the x-axis on graph below shows changes over time [negative = improved; positive = worsened] between the two timepoints rated by respondents on the 10-point Brief Family Stress Index scale)

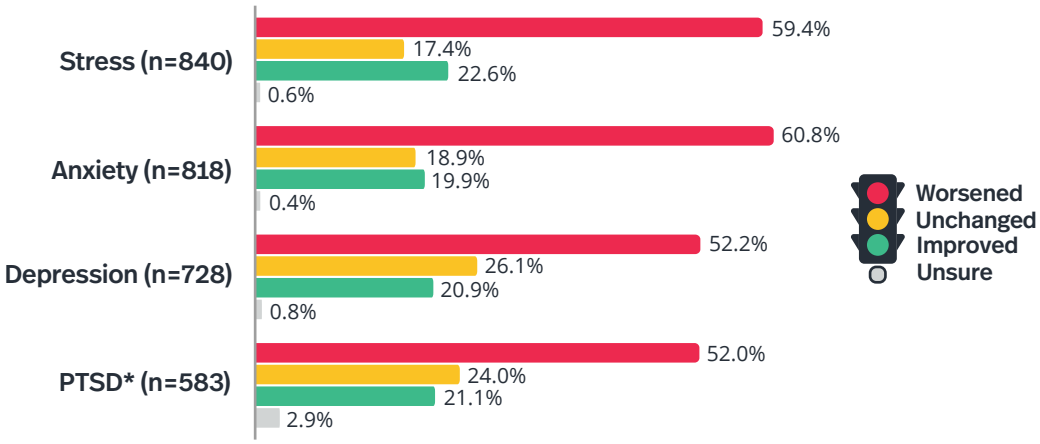


- The average change in family distress from the most stressful part of the COVID-19 pandemic was -0.81 (improvement) for non-autistic caregivers and +0.05 for autistic caregivers. The difference between the two was statistically significant (p=0.00033)

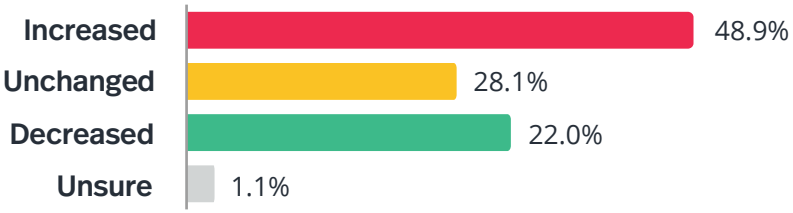
The questions above about family distress were adapted from the 10-level Brief Family Distress Scale. Weiss, J. A., & Lunsky, Y. (2010). The Brief Family Distress Scale: A Measure of Crisis in Caregivers of Individuals with Autism Spectrum Disorders. Journal of Child and Family Studies, 20(4), 521–528. http://doi.org/10.1007/s10826-010-9419-y

4.2 Caregivers

- Change in caregiver mental health from before the COVID-19 pandemic

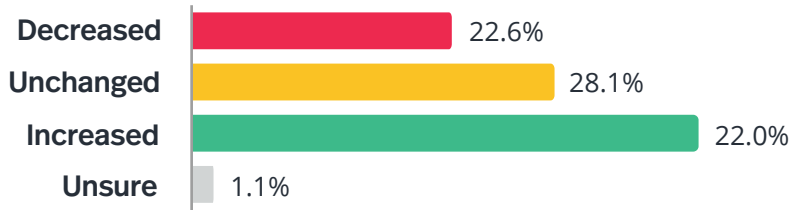


- Change in use of negative coping strategies (e.g., alcohol, over-eating) from worst part of the COVID-19 pandemic to now (n=710)



Note, red applies to increased use of negative coping strategies in the graph above because this would typically be undesirable.

- Change in use of positive coping strategies (e.g., mindfulness, positive affirmations) from worst part of the COVID-19 pandemic to now (n=835)

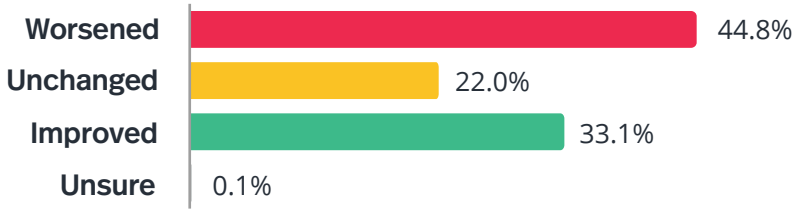


** Respondents were asked to report on post-traumatic stress disorder, or symptoms from past experiences of traumatic events.*

4.2 Caregivers

Social life

- Impact of the COVID-19 pandemic on ability to spend time with friends or other important people (n=902)



Employment

- Among caregiver respondents (n=931), 73.9% reported being employed at some point during the COVID-19 pandemic (i.e., from March 2020 to survey completion fall 2023)

- Change in level of employment from before the COVID-19 pandemic (n=667)

- Of those who reported being employed (n=686), 49.9% reported fully interrupting their employment at some point due to COVID-19 pandemic
- Of those who reported interrupting their employment (n=342), 11.7% reported NOT resuming employment

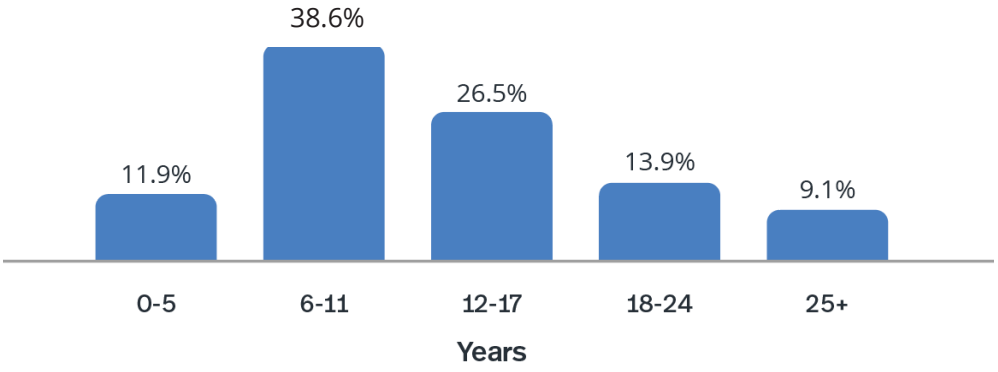
- Change in income (from all sources) from before the COVID-19 pandemic (n=421)

4.3 Autistic Children

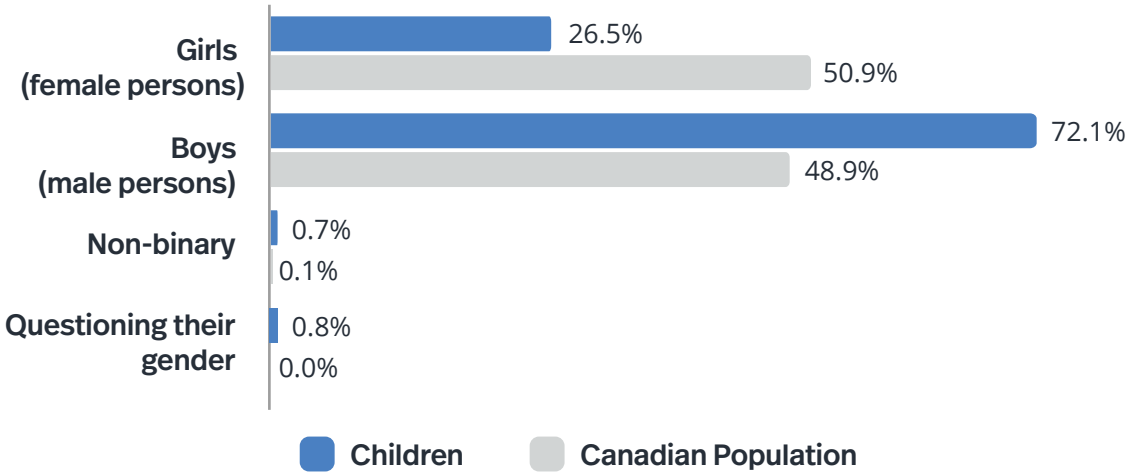
4.3.a About the autistic children of any age (reported on by caregivers)

Basic demographics

- Child ages in years (n=901)



- Child gender identity (n=892)

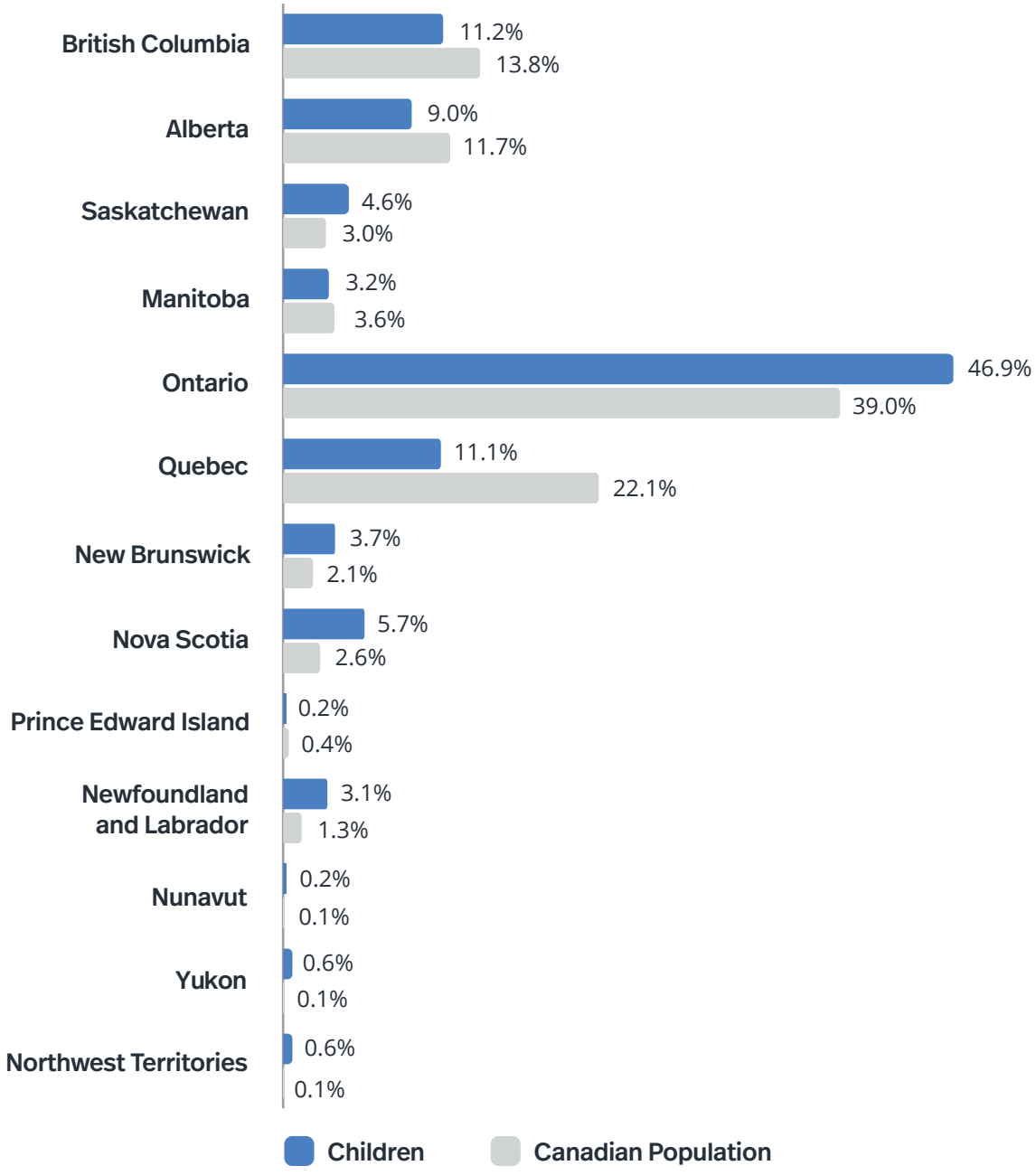


Canadian population data from Canada Census 2021 (source: https://www150.statcan.gc.ca/n1/daily-quotidien/220427/t002b-eng.htm); note, "questioning their gender" was not an option in the Canada Census 2021 and was set to 0%.

4.3 Autistic Children

Geography and language

- Province/Territory of residence (n=898)

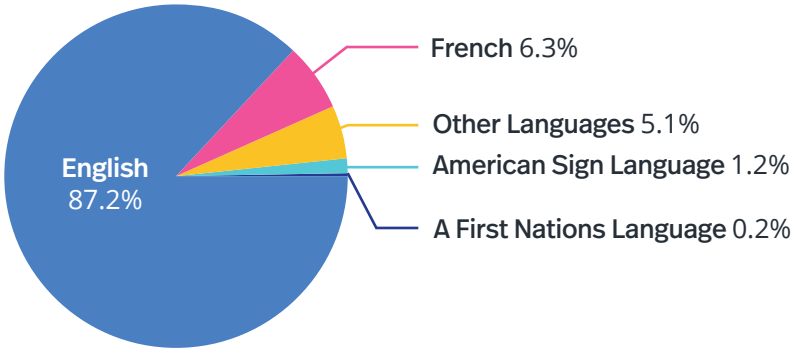


- 12.8% of children (n=894) live in a wide-area rural region*

**Wide-area rural region is based on the second digit of the postal code and provides only a rough estimate of rurality. There was not enough information to differentiate whether people lived in urban or suburban areas.*

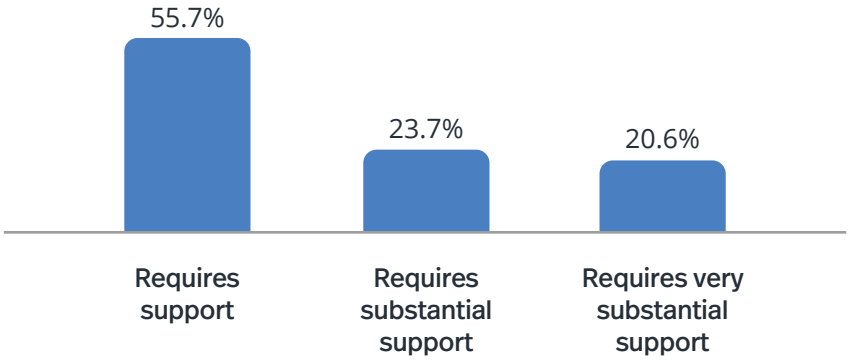
4.3 Autistic Children

Languages most often used at home (n=901)



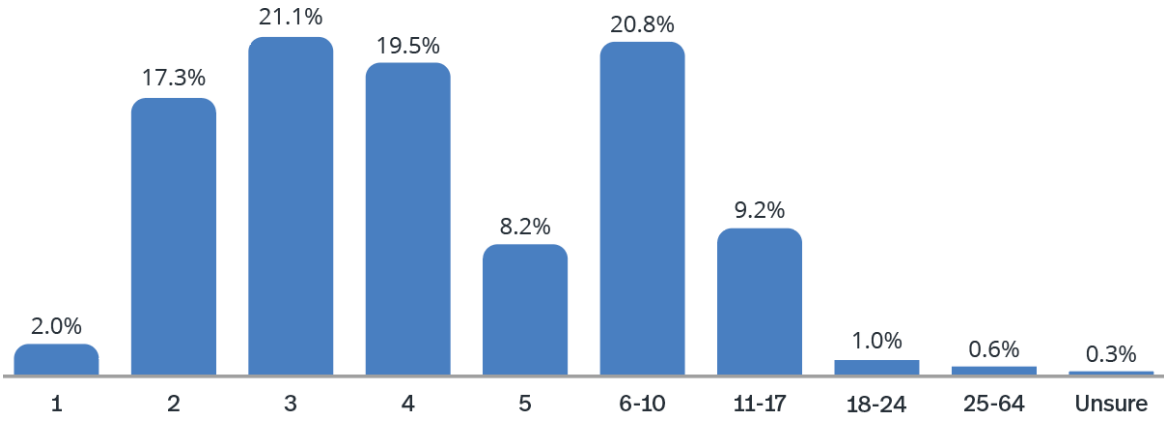
Level of support needs

- Child's current level of support needs (n=890)



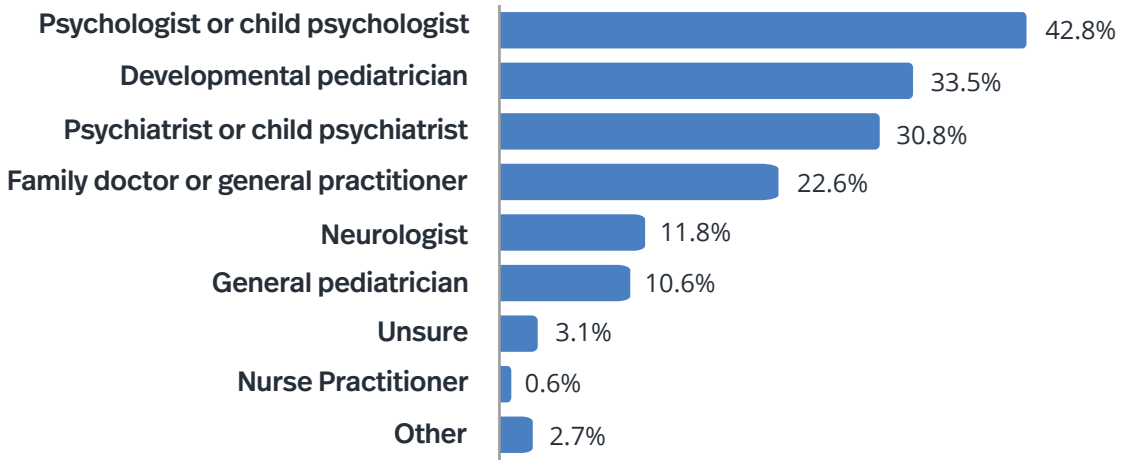
Autism diagnosis

- Age at diagnosis in years (n=902)



4.3 Autistic Children

- Professionals who diagnosed child (multiple selections possible, n=899)
  Note, the types of professionals who are considered qualified to participate in diagnostic assessments of autism varies across the different provinces and territories.



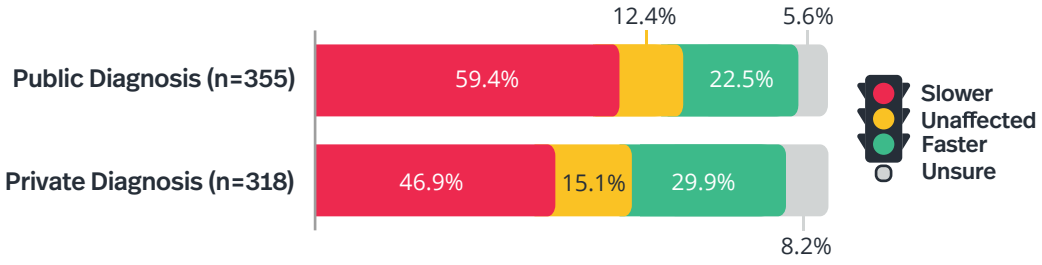
Note, "Other" diagnosing professionals consisted primarily of occupational therapists, speech and language pathologists, and some social workers.

- Of the children reported on (n=898), caregivers reported being in the process of seeking a diagnosis for 42.7% of them at some point during the COVID-19 pandemic (i.e., from March 2020 to survey completion fall 2023

4.3.b Effects of the COVID-19 pandemic on children's autism-related services and supports

Obtaining a diagnosis

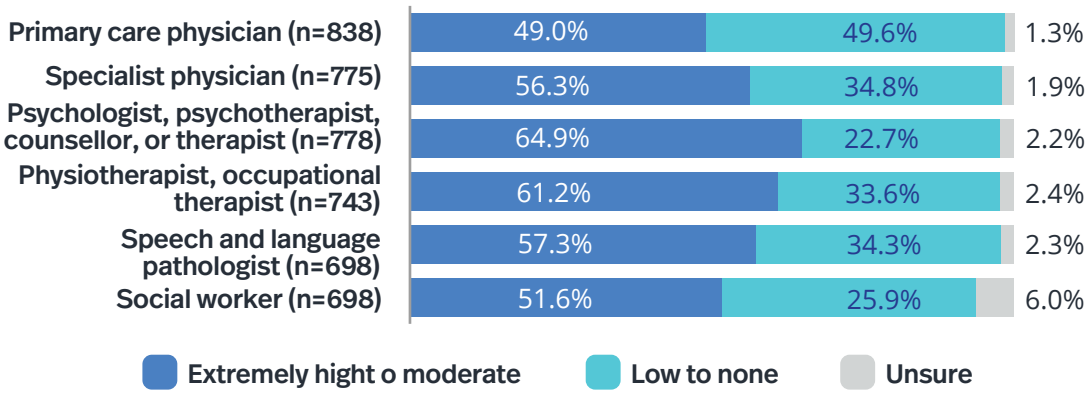
- Effect of COVID-19 pandemic on speed of obtaining a diagnosis (for those seeking one since March 2020)



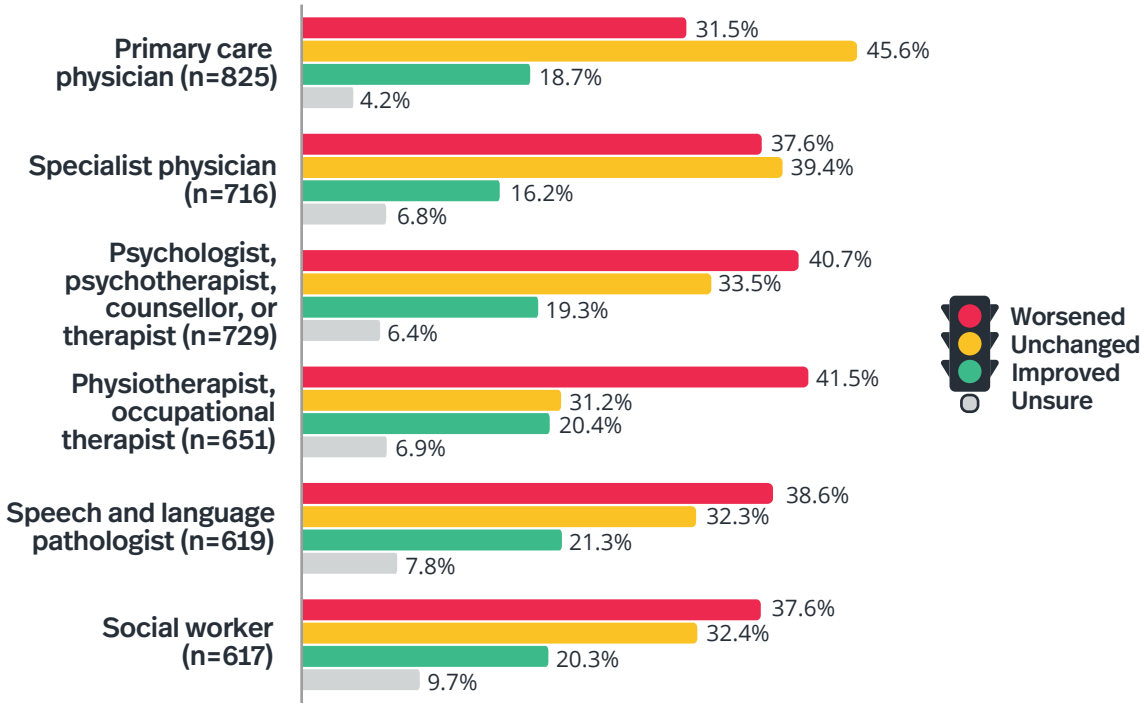
4.3 Autistic Children

Healthcare services

- Current level of unmet needs for health professional services for this child



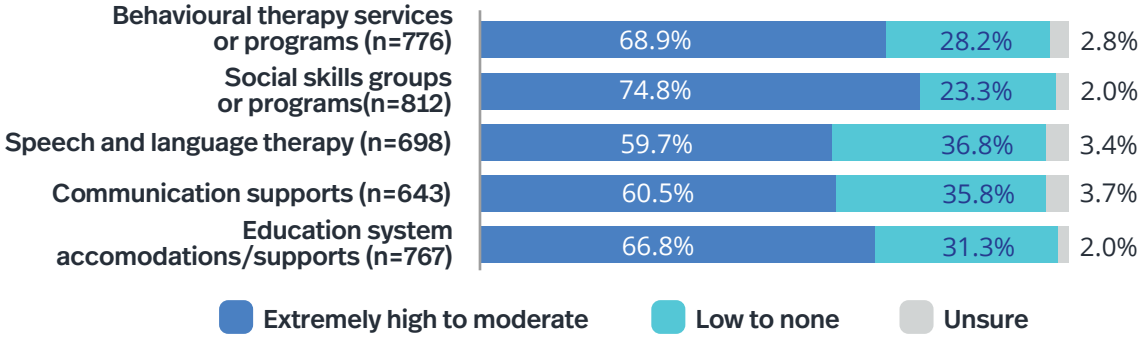
- Perceived change in access to health professional services for this child from before COVID-19 pandemic to now



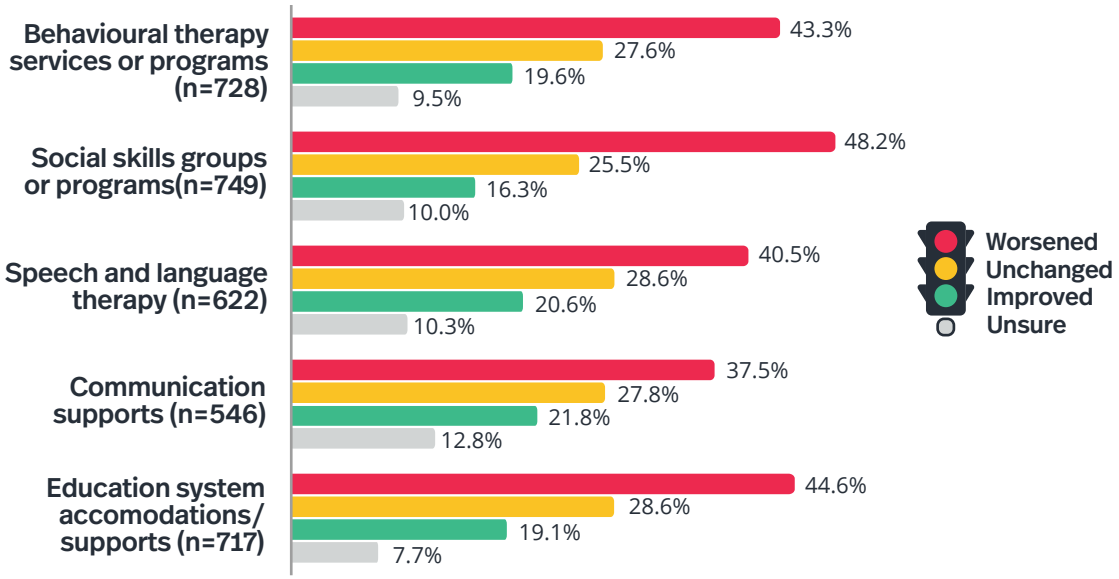
4.3 Autistic Children

Autism- or development-related supports and programs

- Current level of unmet needs for autism- or development-related supports and programs

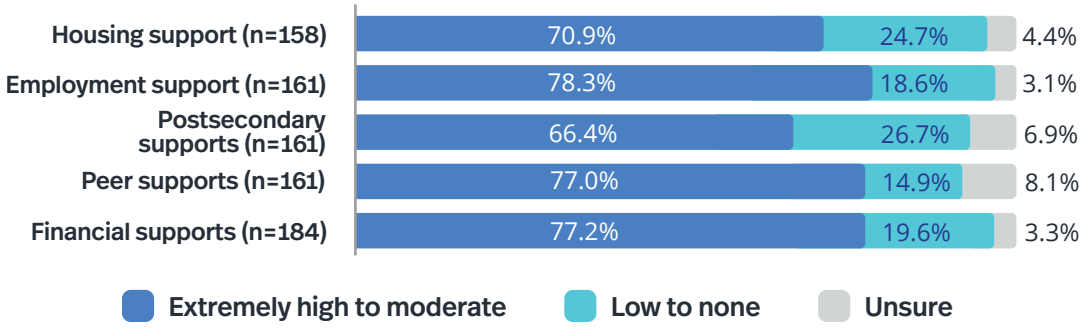


- Perceived change in access to autism- or development-related supports and programs from before COVID-19 pandemic to now

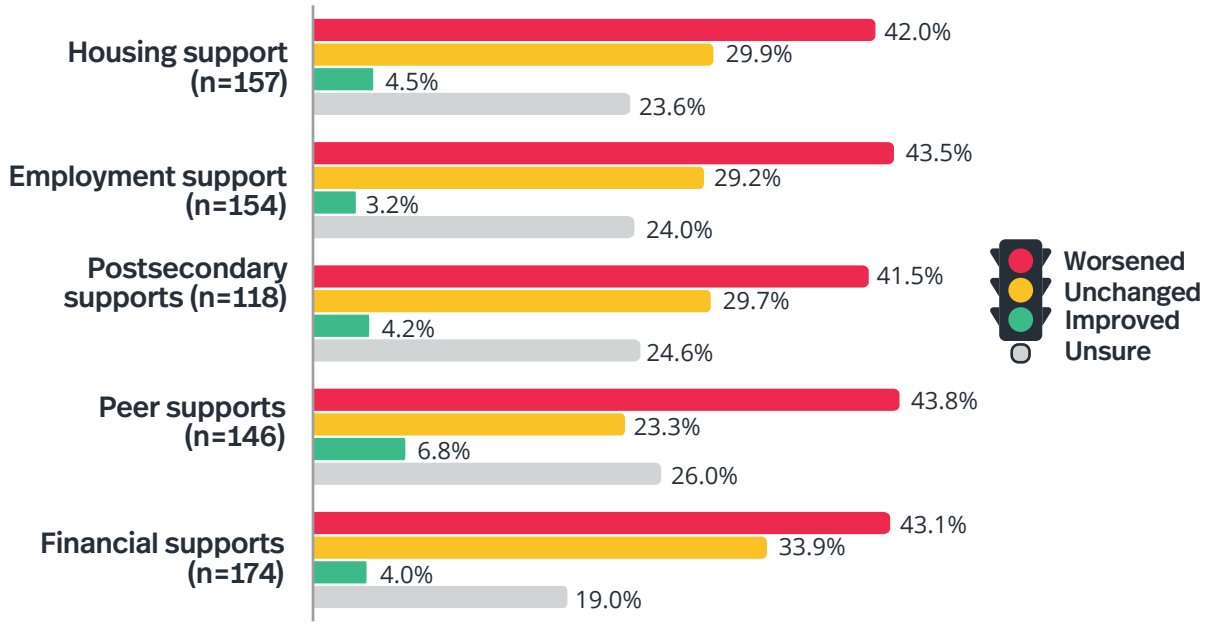


4.3 Autistic Children

- Current level of unmet needs for autistic adult-relevant supports and programs (for children 18+)



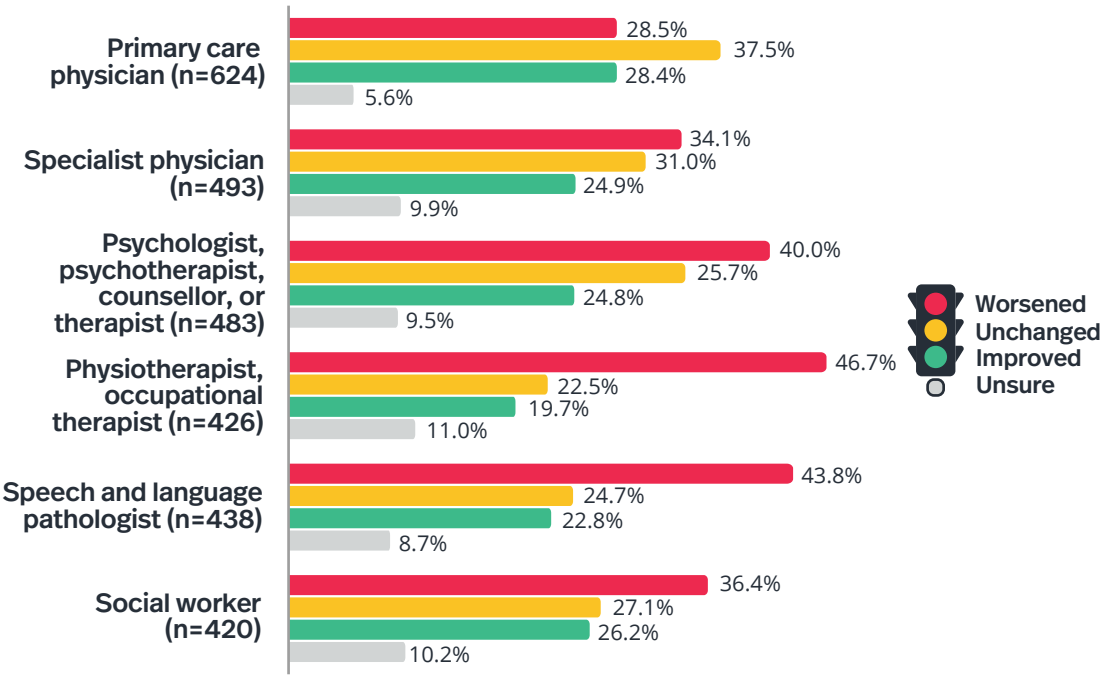
- Perceived change in access to autistic adult-relevant supports and programs from before COVID-19 pandemic to now (for children 18+)



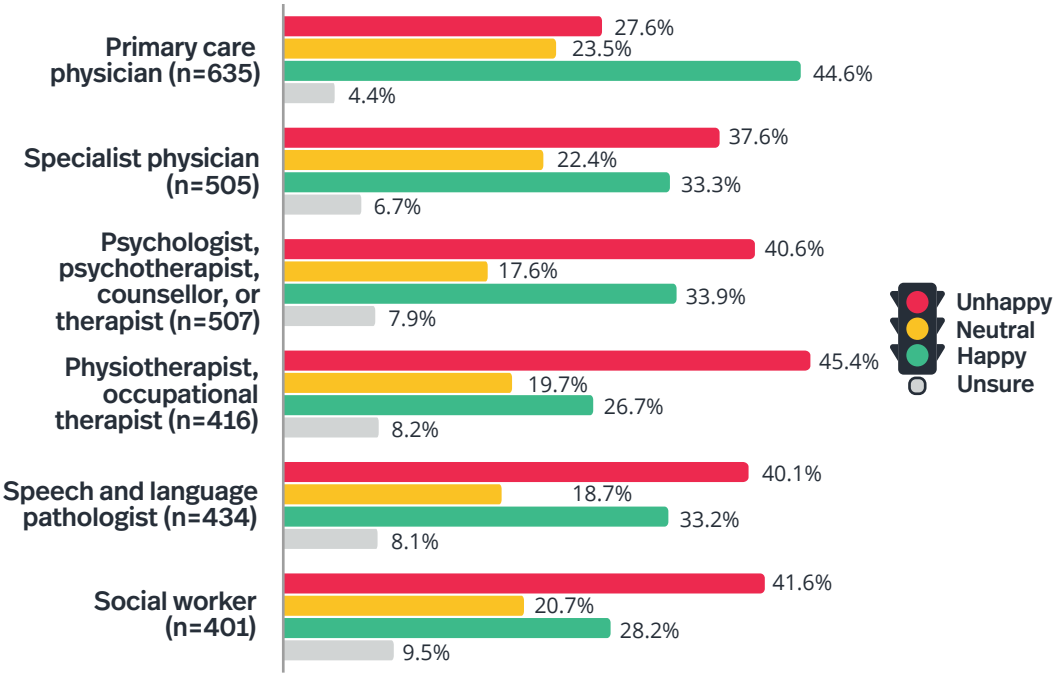
4.3 Autistic Children

In-person versus remote services and supports for this child

- Effect of shift to remote delivery of health professional services for this child on accessibility



- Happiness with availability of health professional services for this child via remote delivery

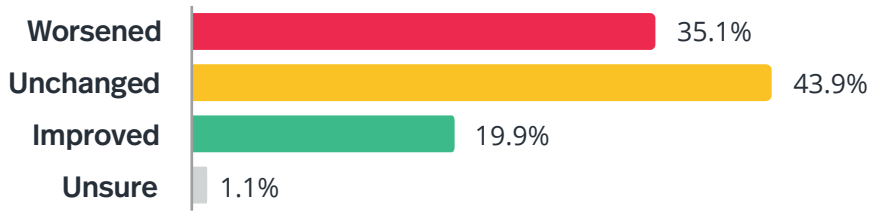


4.3 Autistic Children

4.3.c Impacts of the COVID-19 pandemic on caregivers' autistic children of any age

Child general health

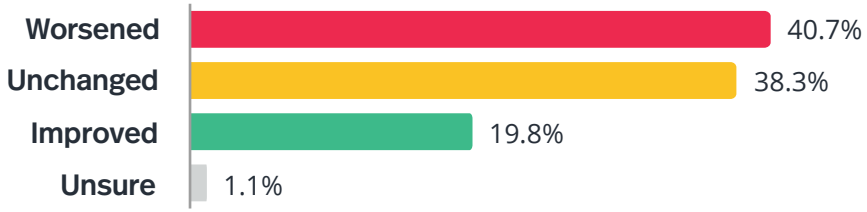
- Change in child's general health from before COVID-19 pandemic to now (n=795)



Healthy habits (physical activity, sleep, eating habits)

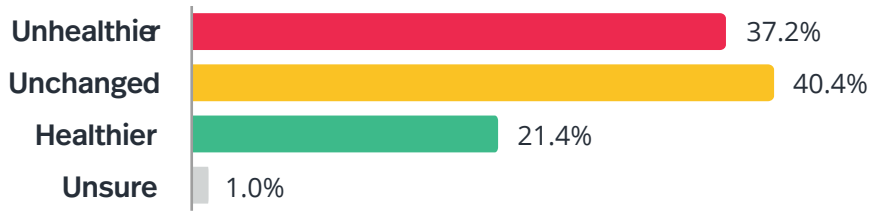
- Change in child's level of daily physical activity from before COVID-19 pandemic to now (n=797)

- Change in child's sleep habits from before COVID-19 pandemic to now (n=796)



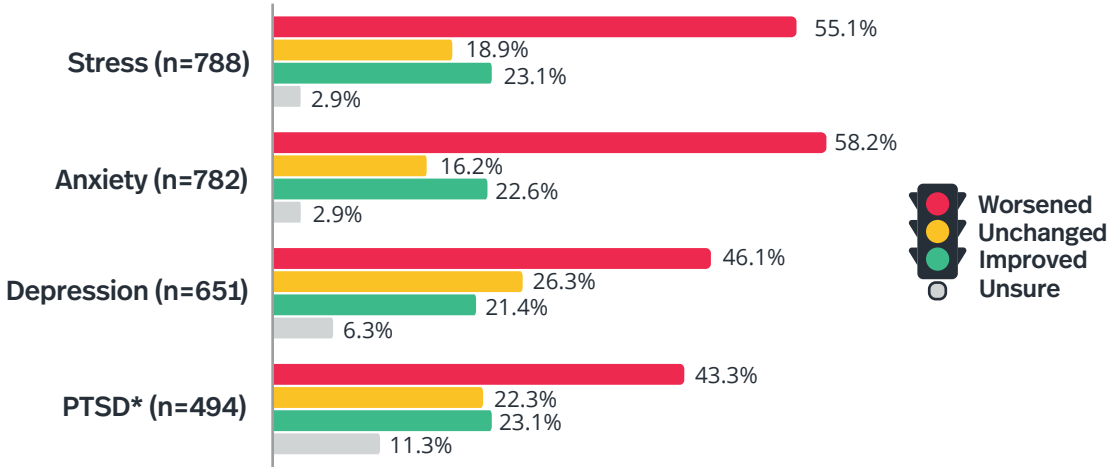
4.3 Autistic Children

- Change in child's eating habits from before COVID-19 pandemic to now (n=795)

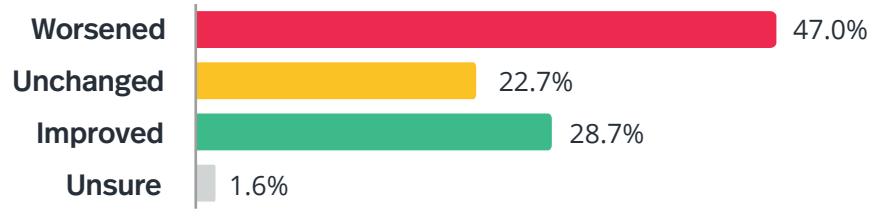


Child mental health (stress, anxiety, depression, ability to cope)

- Change in child's mental health from before COVID-19 pandemic to now



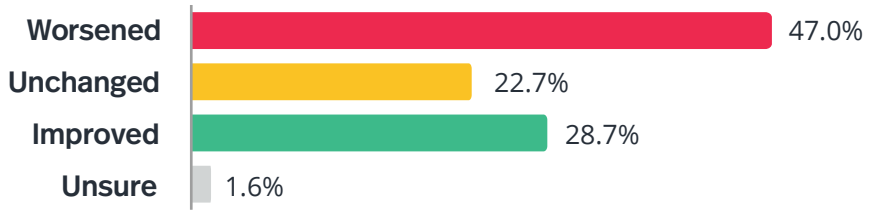
- Change in child's ability to regulate emotions from before COVID-19 pandemic to now (n=798)



** Respondents were asked to report on post-traumatic stress disorder, or symptoms from past experiences of traumatic events.*

4.3 Autistic Children

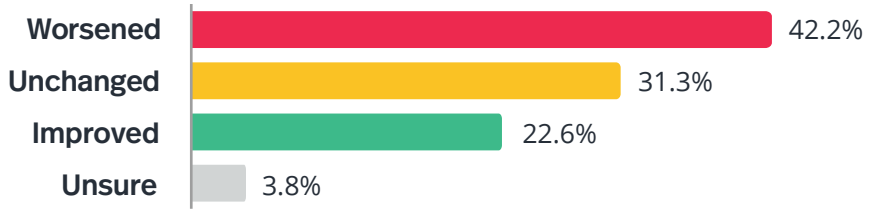
- Change in frequency of meltdowns for this child from before COVID-19 pandemic to now (n=765)



- Change in frequency of engaging in self-harm for this child from before COVID-19 pandemic to now (n=448)

Mental focus and concentration

- Change in child's ability to mentally focus or concentrate from before COVID-19 pandemic to now (n=817)



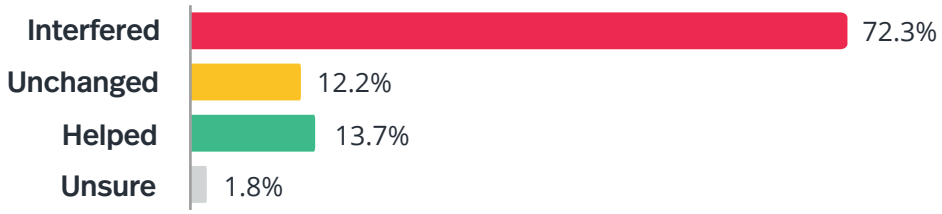
Academic performance in school

- Change in child's ability to meet academic demands (school) from before COVID-19 pandemic to now (n=682)

4.3 Autistic Children

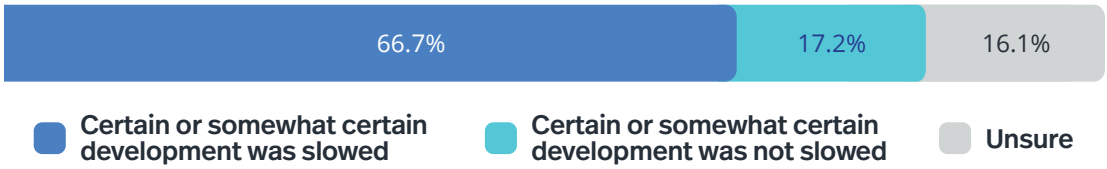
Social development

- Effect of COVID-19 pandemic on child's social development (learning how to interact with others) (n=801)



Developmental

- Certainty about effect of COVID-19 pandemic on child's rate of development



Homelife skills (bathroom, feeding, dressing, etc.)

- Effect of COVID-19 pandemic on child's daily living skills in the home (N=760)

5 Appendix A: Cross-analyses

The cross-analyses below were planned before seeing the data, and provide preliminary answers about how the results from one question may vary according to something else measured by another question in the survey—such as how autistic adults' general health varied by their access to health professional services. Some cross-analyses are not shown below because they did not meet our criteria of importance for reporting (significance, combined with judgments about relevance), but are available upon request. Approximately 250 cross-analyses were conducted, most of which were from crossing multiple-item questions resulting in numerous related cross-analyses (see below).

How to interpret a significant p-value for cross-analyses:

Each cross-analysis below involves a test of significance (usually a chi-squared [or $\chi 2$] test), that allows for the calculation of a p-value. The p-value indicates the probability that variation in the results of one question (variable X) that is observed when there are differences or variation in the responses to another question (variable Y), is due to chance alone and therefore does not reflect true variation—specifically for this group of survey respondents. Significance level: We generally interpret p-values of less than 0.05 as indicating that there was significant variation in variable X by variable Y (in this sample). Correcting the significance level for multiple comparisons: A p-value of less than 0.05 is commonly used as a cut-off to decide that a test (such as a chi-squared test) is statistically significant. The more tests that are done, the higher the chance that a p-value will be below 0.05 by chance, leading the interpretation of significance to be wrong. In cross-analyses, we used the Holm-Bonferroni method to reduce the significance level (the probability to which a statistical test's p-value was compared to determine significance) for singlecrossings (i.e., between a single pair of questions) in which the component questions included multiple items, resulting in involving multiple related chi-squared tests. The Holm-Bonferroni method (testsing only the lowest p-value against the strictest criterion, and the higher p-values against progressively less strict criteria). This is because the more tests that are done, the higher the chance that a p-value will be below 0.05 by chance, leading the interpretation of significance to be wrong. The highest number of related tests for (cross-analyses) within a single crossing of multiple-item questions was 24. Since multiple comparisons were also done across all different crossings of survey questions analyses (i.e., in addition to the multiple comparisons WITHIN single crossings of multiple-item questions) in this Appendix, it is also possible that some of the single-test crossings (i.e., of single-item questions) for which the significance level was uncorrected were also at risk of this error (of mistakenly interpreting a p-value to indicate significance). The p-values provided for these tests can help with judgments about the level of this risk of this error (i.e., risk of this error would be lower for p-values that are progressively farther below 0.05 would have a lower risk of this error).

5 Appendix A: Cross-analyses

The single-test crossings presented all had p-values below 0.01, although even this level is at risk of error given the high number of tests that were conducted altogether.

How to interpret "percent difference from expected":

To illustrate the (statistically significant) cross-analyses in more detail, we provide the corresponding tables of "percent difference from expected." These tables can be used to see specifically where the variations (differences from expected) between two variables may be. For any cell in the table, larger numbers (either positive or negative) indicate larger deviations above or below what would be expected (i.e., column total x row total / grand total). We interpret differences greater then +/-10% as indicating an greater-than-expected increase or decrease. However, there is still some uncertainty in whether (or how accurately) these differences reflect true differences. The differences in these tables should not be interpreted as applying to the entire population across Canada given limitations of the sample.

The statements above tables that summarize their findings should be interpreted as applying to the survey sample only, and that more research is needed to confirm them in the broader population.

5 Appendix A: Cross-analyses

5.a Variations in unmet needs and accessibility of services and supports

Variations by caregiver autistic status

1. Variation in level of **unmet personal needs of CAREGIVERS for health professional services by caregiver autistic status.**

There was significant variation in caregivers' level of unmet personal needs for all types of health professional services (including from primary care physicians, specialist physicians, psychologist and psychotherapeutic service providers, physio- and occupational therapists, and social workers) according to their autistic status (autistic versus non-autistic). Higher-than-expected proportions of autistic caregivers consistently reported "moderately to extremely high" unmet needs for all types of health professional services.

		Autistic Status			
Primary care physician	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	-27.40%	61	6.20%	396
	Moderate to extremely high	22.20%	127	-5.00%	438

p=0.00018, χ2 (1) =14

		Autistic Status			
Specialist Physician	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	-32.50%	47	7.20%	309
	Moderate to extremely high	19.90%	136	-4.80%	444

p=0.00012, χ2 (1) =14.8

5 Appendix A: Cross-analyses

		Autistic Status			
Psychologist, psychotherapist, counsellor, or therapist	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	-25.90%	41	6.10%	247
	Moderate to extremely high	10.90%	146	-2.60%	540

p=0.0108, χ2 (1) =6.5

		Autistic Status			
Physiotherapist, occupational therapist	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	-20.80%	56	4.90%	316
	Moderate to extremely high	14.10%	119	-3.30%	430

p=0.01195, χ2 (1)=6.3

		Autistic Status			
Social Worker	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	-27.00%	54	6.40%	330
	Moderate to extremely high	21.50%	113	-5.10%	370

p=0.00054, χ2 (1) =12

2. Variation in level of **unmet personal needs of CAREGIVERS for care navigation supports by caregiver autistic status.**

There was significant variation in caregivers' level of unmet personal needs for care navigation supports according to their autistic status (autistic versus non-autistic). Higher-than-expected proportions of autistic caregivers reported "low or no" unmet needs for care navigation supports.

		Autistic Status			
Unmet care navigation support needs	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	32.20%	53	-6.40%	190
	Moderate to extremely high	-10.80%	107	2.10%	620

p=0.00991, χ2 (1)=6.7

5 Appendix A: Cross-analyses

3. Variation in level of **unmet needs of autistic CHILDREN for autism- or development-related supports by caregiver autistic status.**

There was significant variation in children's level of unmet needs for all types of autism- or development-related supports (including behavioural therapy services, social skills groups, speech and language therapy, communication supports, and education system supports) according to the autistic status of their caregivers (autistic versus non-autistic). Higher-than-expected proportions of autistic caregivers consistently reported "low or no" unmet needs for their child(ren), for all types of supports.

		Autistic Status			
Behavioural therapy services or programs	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	+31.5%	55	-7.4%	164
	Moderate to extremely high	-12.9%	89	+3.0%	446

p=0.00717, χ2 (1) =7.2

		Autistic Status			
Social skills groups or programs	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	+44.2%	51	-10.2%	138
	Moderate to extremely high	-13.7%	98	+3.2%	509

p=0.00085, χ2 (1) =11.1

		Autistic Status			
Speech and language therapy	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	+23.6%	66	-6.2%	191
	Moderate to extremely high	-14.6%	74	+3.8%	343

p=0.01364, χ2 (1) =6.1

		Autistic Status			
Communication supports	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	+22.7%	62	-6.4%	168
	Moderate to extremely high	-13.4%	74	+3.8%	315

p=0.02125, χ2 (1) =5.3

		Autistic Status			
Education system accommodations/ support	% Difference from Expected	Autistic	n	Not Autistic	n
	Low or none	+26.6%	61	-6.7%	179
	Moderate to extremely high	-12.5%	90	+3.1%	422

p=0.01238, χ2 (1) =6.3

5.b Variations in health (including mental health)

4. Variation in how **AUTISTIC ADULTS' general health** changed from before COVID-19 pandemic to now, **by their change in access to disability- or autism-related supports and programs.**

Changes in autistic adults' general health varied significantly by their change in access to all types of **disability- or autism-related supports** (including those related to housing, employment, postsecondary education, communication, finances, and from peers). Higher-than-expected proportions of autistic adults reported **improved general health** with **improved access** to each type of disability- or autism-related support; and **worsened general health** with **worsened access** to each type of disability- or autism-related support.

General Health		Housing Supports					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	70.10%	58	-34.20%	16	-60.90%	10
	Unchanged	-8.90%	27	23.00%	26	-10.00%	20
	Worsened	-48.00%	23	10.90%	35	53.70%	51

p<0.00001, χ2 (4) >28.5

General Health		Employment Supports					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	49.20%	46	-19.70%	22	-36.50%	17
	Unchanged	-9.30%	25	22.50%	30	-12.30%	21
	Worsened	-31.10%	28	-0.30%	36	36.00%	48

p=0.00016, χ2 (4) >22.5

5 Appendix A: Cross-analyses

		Post-Secondary Supports					
General Health	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	50.30%	51	-30.20%	20	-37.50%	14
	Unchanged	-18.80%	24	32.20%	33	-12.80%	17
	Worsened	-29.20%	28	1.80%	34	41.80%	37

p=0.00003, χ2 (4) =26.1

		Alternate Communication Supports					
General Health	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	50.00%	51	-25.70%	19	-38.00%	17
	Unchanged	-20.00%	25	36.10%	32	-8.80%	23
	Worsened	-24.60%	33	-5.80%	31	35.90%	48

p=0.00003, χ2 (4) =26.1

		Peer Supports					
General Health	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	50.60%	48	-32.20%	19	-30.80%	16
	Unchanged	-15.90%	21	23.10%	27	-6.10%	17
	Worsened	-35.60%	22	13.20%	34	33.10%	33

p=0.00015, χ2 (4) =26.5

		Financial Supports					
General Health	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	28.10%	36	19.70%	34	-44.30%	17
	Unchanged	0.60%	26	14.90%	30	-14.50%	24
	Worsened	-20.70%	31	-24.00%	30	41.40%	60

p=0.00023, χ2 (4) =21.7

5 Appendix A: Cross-analyses

5. Variation in how **AUTISTIC ADULTS' general health** changed from before COVID-19 pandemic to now, by their **change in access to health professional services.**

Changes in autistic adults' general health varied significantly by their change in access to all types of health professional services (including from primary care physicians, specialist physicians, psychologist and psychotherapeutic service providers, physio- and occupational therapists, speech and language pathologists, and social workers). Higher-than-expected proportions of autistic adults reported **improved general health** with **improved access** to each type of health professional service; and **worsened general health** with **worsened access** to each type of health professional service.

		Primary care physician					
General Health	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	65.20%	51	-27.20%	19	-35.20%	24
	Unchanged	-19.70%	24	30.60%	33	-5.20%	34
	Worsened	-28.90%	35	-1.50%	41	25.20%	74

p<0.00001, χ2(4) >28.5

		Specialist Physician					
General Health	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	82.60%	51	-21.40%	21	-47.70%	19
	Unchanged	-1.40%	23	7.50%	24	-4.40%	29
	Worsened	-54.50%	19	10.10%	44	34.40%	73

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

General Health		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	43.30%	48	-34.30%	14	-19.30%	30
	Unchanged	-0.70%	34	33.30%	29	-18.40%	31
	Worsened	-28.40%	36	0.20%	32	25.50%	70

p=0.00025, χ2 (4) =21.5

General Health		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	46.70%	48	-18.90%	22	-32.60%	21
	Unchanged	2.10%	29	6.20%	25	-7.60%	25
	Worsened	-36.20%	28	10.00%	40	29.20%	54

p=0.00027, χ2 (4) =21.3

General Health		Speech and language pathologist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	32.10%	45	-23.40%	23	-18.60%	17
	Unchanged	-5.50%	25	-1.40%	23	11.00%	18
	Worsened	-29.20%	23	25.70%	36	10.50%	22

p=0.02612, χ2 (4) =11

		Social worker					
General Health	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	38.70%	43	0.00%	24	-34.30%	23
	Unchanged	19.30%	30	2.70%	20	-19.00%	23
	Worsened	-45.70%	20	-1.90%	28	41.80%	59

p=0.00004, χ2 (4) =25.5

6. Variation in how **CAREGIVERS' general health** changed from before COVID-19 pandemic to now, by their **change in access to health professional services.**

Changes in caregivers' general health varied significantly by their change in access to all types of health professional services (including from primary care physicians, specialist physicians, psychologist and psychotherapeutic service providers, physio- and occupational therapists, and social workers). Higher-than-expected proportions of caregivers reported **improved general** health with **improved access** to each type of health professional service; and **worsened general health** with **worsened access** to each type of health professional service.

		Primary Care Physician					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	+88.7%	73	-15.1%	62	-27.9%	60
	Unchanged	-10.4%	43	+22.4%	111	-14.8%	88
	Worsened	-34.8%	55	-5.8%	150	+21.3%	220

p<0.00001, χ2 (4) >28.5

		Specialist Physician					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	+132.3%	80	-17.4%	49	-42.3%	48
	Unchanged	-18.2%	32	+39.5%	94	-20.7%	75
	Worsened	-54.6%	32	-13.5%	105	+32.2%	225

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

		Psychologist, psychotherapist, counsellor, or therapist					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	+94.3%	78	-23.9%	42	-30.2%	57
	Unchanged	-22.2%	36	+46.3%	93	-20.3%	75
	Worsened	-32.6%	57	-14.0%	100	+25.5%	216

p<0.00001, χ2(4) >28.5

		Physiotherapist, occupational therapist					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	+97.8%	72	-16.5%	53	-36.3%	44
	Unchanged	-20.1%	32	+31.7%	92	-18.5%	62
	Worsened	-38.5%	44	-9.4%	113	+28.9%	175

p<0.00001, χ2(4) >28.5

		Social Worker					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	+64.4%	47	+4.8%	61	-30.6%	48
	Unchanged	+0.2%	29	+27.2%	75	-22.9%	54
	Worsened	-37.3%	31	-18.6%	82	+31.1%	157

p<0.00001, χ2(4) >28.5

5 Appendix A: Cross-analyses

7. Variation in how **CHILDRENS' general health** changed from before COVID-19 pandemic to now, by the **change in access to autism-or development-related supports and programs.**

Changes in children's general health varied significantly by their change in access to all types of autism- or development-related supports (including behavioural therapy services, social skills groups, speech and language therapy, communication supports, and education system supports). Higher-than-expected proportions of children were reported to have **improved general health** with **improved access** to each type of autism- or development-related support; and **worsened general health** with **worsened access** to each type of autism- or development-related support.

		Behavioural therapy services or programs					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	119.00%	67	-13.70%	36	-46.70%	35
	Unchanged	-37.30%	35	37.90%	105	-6.70%	112
	Worsened	-32.00%	33	-35.00%	43	37.10%	143

p<0.00001, χ2 (4) >28.5

		Social skills groups or programs					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	142.90%	59	0.70%	37	-49.30%	36
	Unchanged	-34.10%	32	27.90%	94	-2.80%	138
	Worsened	-43.00%	24	-32.60%	43	31.60%	162

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

		Speech and language therapy					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	94.80%	56	-7.30%	37	-44.00%	31
	Unchanged	-36.10%	32	30.90%	91	-3.50%	93
	Worsened	-21.80%	33	-31.70%	40	34.20%	109

p<0.00001, χ2 (4) >28.5

		Communication supports					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	86.50%	58	-15.60%	32	-41.20%	30
	Unchanged	-40.80%	25	51.50%	78	-13.40%	60
	Worsened	-23.80%	31	-41.50%	29	45.40%	97

p<0.00001, χ2 (4) >28.5

		Education system accommodations/ supports					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	121.60%	63	-16.90%	35	-42.00%	38
	Unchanged	-27.70%	39	31.50%	105	-8.20%	114
	Worsened	-42.10%	27	-26.10%	51	35.10%	145

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

8. Variation in how **CHILDRENS' general health** changed from before COVID-19 pandemic to now, by their **change in access to health professional services.**

Changes in childrens' general health varied significantly by their change in access to all types of health professional services (including from primary care physicians, specialist physicians, psychologist and psychotherapeutic service providers, physio- and occupational therapists, speech and language pathologists, and social workers). Higher-than-expected proportions of children were reported to have **improved general health** with **improved access** to each type of health professional service; and **worsened general health** with **worsened access** to each type of health professional service.

		Primary care physician					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	119.50%	64	-26.30%	52	-34.50%	31
	Unchanged	-26.80%	46	24.20%	189	-19.60%	82
	Worsened	-35.30%	33	-14.90%	105	43.90%	119

p<0.00001, χ2 (4) >28.5

		Specialist physician					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	118.60%	50	-13.70%	47	-38.10%	32
	Unchanged	-30.60%	31	32.60%	141	-20.80%	80
	Worsened	-33.20%	27	-28.30%	69	44.50%	132

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

		Psychologist, psychotherapist, counsellor, or therapist					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	116.70%	65	-9.60%	46	-50.90%	29
	Unchanged	-21.30%	43	28.40%	119	-13.60%	93
	Worsened	-46.40%	27	-25.10%	64	45.10%	144

p<0.00001, χ2 (4) >28.5

		Physiotherapist, occupational therapist					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	104.60%	61	-10.20%	39	-46.30%	31
	Unchanged	-21.20%	40	23.10%	91	-6.40%	92
	Worsened	-44.00%	26	-18.70%	55	36.80%	123

p<0.00001, χ2 (4) >28.5

		Speech and language pathologist					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	110.90%	63	-16.50%	37	-49.80%	26
	Unchanged	-37.80%	32	21.80%	93	3.10%	92
	Worsened	-32.00%	29	-14.70%	54	31.10%	97

p<0.00001, χ2 (4) >28.5

		Social Worker					
General Health Change	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	95.90%	55	-22.50%	34	-34.00%	33
	Unchanged	-36.40%	29	23.50%	88	-0.20%	81
	Worsened	-22.80%	35	-9.70%	64	21.30%	98

$p<0.00001$, $\chi 2$ (4) >28.5

Variations in how mental health changed from before the COVID-19 pandemic by changes in access to different supports

9. Variation in how **AUTISTIC ADULTS' mental health** changed from before COVID-19 pandemic to now, by their **change in access to disability- or autism-related supports and programs.**

Changes in autistic adults' mental health (including stress, anxiety, depression, and symptoms from past experiences of traumatic events) varied significantly by their change in access to different types of **disability- or autism-related supports** (including those related to housing, employment, postsecondary education, communication, peers, and finances) with some exceptions. Exceptions: symptoms from past experiences of traumatic events by access to postsecondary education-, communication-, or peer-supports; anxiety by peer supports; depression by postsecondary education- or peer-supports. Generally, higher-than-expected proportions of autistic adults reported **improved mental health** with **improved access** to each type of disability- or autism-related support; and **worsened mental health** with **worsened access** to each type of disability- or autism-related support.

		Housing Supports					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	42.50%	51	-27.80%	21	-26.30%	20
	Unchanged	-11.60%	11	38.30%	14	-25.80%	7
	Worsened	-32.20%	29	12.10%	39	29.50%	42

$p=0.00037$, $\chi 2$ (4) =20.7

5 Appendix A: Cross-analyses

		Employment Supports					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	51.60%	48	-14.70%	27	-36.80%	20
	Unchanged	10.00%	11	20.00%	12	-30.00%	7
	Worsened	-44.10%	22	6.80%	42	37.30%	54

p=0.00001, χ2 (4) =28.5

		Postsecondary Supports					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	47.90%	50	-15.40%	25	-45.40%	14
	Unchanged	-2.50%	10	0.40%	9	2.80%	8
	Worsened	-37.10%	27	12.00%	42	35.10%	44

p=0.00007, χ2 (4) =24.3

		Alternate Communication Supports					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	38.80%	49	-17.80%	22	-28.00%	23
	Unchanged	-21.70%	10	34.40%	13	-4.80%	11
	Worsened	-23.30%	36	4.00%	37	22.40%	52

p=0.00435, χ2 (4) =15.2

5 Appendix A: Cross-analyses

		Peer Supports					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	34.90%	45	-13.40%	27	-29.30%	18
	Unchanged	9.90%	11	-35.80%	6	30.90%	10
	Worsened	-38.70%	20	24.70%	38	20.50%	30

p=0.00229, χ2 (4) =16.6

		Financial Supports					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	59.00%	42	0.30%	30	-48.00%	17
	Unchanged	-8.10%	9	26.30%	14	-17.50%	10
	Worsened	-37.20%	25	-6.70%	42	36.20%	67

p<0.00001, χ2 (4) >28.5

		Housing Supports					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	62.30%	45	-20.20%	18	-61.40%	8
	Unchanged	-1.10%	17	-21.30%	11	24.60%	16
	Worsened	-37.10%	29	20.10%	45	27.80%	44

p<0.00001, χ2 (4) >28.5

		Employment Supports					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	74.30%	42	-25.30%	18	-49.60%	12
	Unchanged	-2.70%	14	-2.70%	14	5.50%	15
	Worsened	-41.20%	25	15.30%	49	26.20%	53

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

		Postsecondary Supports					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	51.70%	40	-20.90%	18	-47.00%	10
	Unchanged	-3.30%	15	-10.40%	12	17.10%	13
	Worsened	-28.50%	33	15.50%	46	21.10%	40

p=0.00083, χ2 (4) =18.9

		Communication Supports					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	50.50%	41	-23.60%	16	-37.00%	15
	Unchanged	-19.60%	14	-10.30%	12	31.50%	20
	Worsened	-37.20%	40	16.30%	45	9.10%	48

p=0.00177, χ2 (4)=17.2

		Peer Supports					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	22.60%	32	1.20%	25	-30.60%	14
	Unchanged	-28.40%	10	-16.80%	11	57.40%	17
	Worsened	-5.50%	33	5.90%	35	0.00%	27

p=0.07466, χ2 (4) =8.5

		Financial Supports					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	35.30%	28	28.40%	29	-55.50%	11
	Unchanged	28.60%	18	-34.50%	10	7.60%	18
	Worsened	-26.70%	31	-2.50%	45	24.60%	63

p=0.00029, χ2 (4) =21.2

5 Appendix A: Cross-analyses

		Housing Supports					
Depression	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	49.30%	43	-24.10%	17	-42.30%	12
	Unchanged	-14.80%	15	16.90%	16	2.30%	13
	Worsened	-26.60%	32	9.10%	37	27.00%	40

p=0.001, χ2 (4) =18.5

		Employment Supports					
Depression	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	54.20%	38	-28.30%	17	-27.00%	18
	Unchanged	-3.60%	14	28.90%	18	-24.20%	11
	Worsened	-32.20%	27	7.00%	41	25.50%	50

p=0.00053, χ2 (4) =19.9

		Postsecondary Supports					
Depression	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	31.40%	37	7.00%	25	-51.20%	10
	Unchanged	-10.80%	15	0.40%	14	14.50%	14
	Worsened	-16.30%	36	-4.70%	34	27.80%	40

p=0.01489, χ2 (4) =12.4

5 Appendix A: Cross-analyses

		Alternate Communication Supports					
Depression	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	49.90%	42	-27.60%	15	-32.70%	17
	Unchanged	10.10%	20	-3.20%	13	-8.50%	15
	Worsened	-34.50%	30	18.10%	40	23.40%	51

p=0.00041, χ2 (4) =20.4

		Peer Supports					
Depression	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	35.10%	36	-11.80%	21	-33.50%	13
	Unchanged	7.80%	16	-2.00%	13	-8.20%	10
	Worsened	-31.30%	23	10.30%	33	30.20%	32

p=0.0187, χ2 (4) =11.8

		Financial Supports					
Depression	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	49.30%	32	-7.00%	21	-34.60%	17
	Unchanged	18.20%	17	18.80%	18	-31.30%	12
	Worsened	-33.60%	26	-3.10%	40	30.40%	62

p=0.00049, χ2 (4) =20

5 Appendix A: Cross-analyses

		Housing Supports					
PTSD	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	44.60%	40	-9.90%	18	-53.50%	9
	Unchanged	12.20%	19	30.90%	16	-49.40%	6
	Worsened	-31.70%	31	-5.50%	31	51.00%	48

p=<0.00001, χ2 (4) >28.5

		Employment Supports					
PTSD	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	60.80%	36	-25.60%	16	-36.60%	14
	Unchanged	20.60%	18	11.50%	16	-32.10%	10
	Worsened	-42.00%	23	10.10%	42	32.70%	52

p=0.00002, χ2 (4) =27

		Postsecondary Supports					
PTSD	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	18.70%	30	-1.70%	21	-23.70%	14
	Unchanged	19.60%	20	-0.90%	14	-25.90%	9
	Worsened	-19.00%	34	1.40%	36	24.60%	38

p=0.14942, χ2 (4) =6.8

		Alternate Communication Supports					
PTSD	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	18.80%	31	-21.30%	15	-3.80%	22
	Unchanged	2.00%	18	16.40%	15	-15.90%	13
	Worsened	-11.60%	40	5.90%	35	8.40%	43

p=0.46704, χ2 (4) =3.6

PTSD		Peer Supports					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	32.20%	34	-23.90%	17	-15.60%	16
	Unchanged	-4.70%	15	9.80%	15	-5.10%	11
	Worsened	-21.80%	27	13.30%	34	13.90%	29

p=0.12225, χ2 (4) =7.3

PTSD		Financial Supports					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	43.80%	29	23.00%	28	-56.10%	11
	Unchanged	25.40%	16	11.20%	16	-30.60%	11
	Worsened	-32.60%	25	-16.40%	35	41.10%	65

p=0.00001, χ2 (4) =28.5

10. Variation in how **AUTISTIC ADULTS' mental health** changed from before COVID-19 pandemic to now, by their **change in access to health professional services.**

Changes in autistic adults' mental health (including stress, anxiety, depression, and symptoms from past experiences of traumatic events) varied significantly by their change in access to all types of health professional services (including from primary care physicians, specialist physicians, psychologist and psychotherapeutic service providers, physio- and occupational therapists, speech and language pathologists, and social workers)—with no exceptions. Higher-than-expected proportions of autistic adults reported **improved mental health** with **improved access** to each type of health professional service; and **worsened mental health** with **worsened access** to each type of health professional service.

Stress		Primary care physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	60.90%	50	-28.60%	19	-27.40%	30
	Unchanged	-12.40%	11	11.70%	12	1.80%	17
	Worsened	-32.50%	36	13.90%	52	15.50%	82

p=0.00004, χ2 (4) =25.5

5 Appendix A: Cross-analyses

Stress		Specialist physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	53.50%	44	-8.20%	26	-33.40%	26
	Unchanged	15.10%	11	37.70%	13	-38.50%	8
	Worsened	-37.50%	28	-2.80%	43	29.60%	79

p=0.00001, χ2 (4) =28.5

Stress		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	55.20%	52	-17.80%	18	-35.90%	26
	Unchanged	43.30%	17	41.80%	11	-58.30%	6
	Worsened	-40.30%	35	1.70%	39	32.30%	94

p<0.00001 χ2 (4) >28.5

Stress		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	68.30%	55	-43.00%	16	-32.80%	21
	Unchanged	31.40%	14	9.30%	10	-41.10%	6
	Worsened	-52.70%	23	26.80%	53	31.00%	61

p<0.00001 χ2 (4) >28.5

5 Appendix A: Cross-analyses

		Speech and language pathologist					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	38.50%	48	-31.80%	21	-17.20%	17
	Unchanged	-10.70%	9	45.20%	13	-49.80%	3
	Worsened	-33.80%	24	17.90%	38	30.30%	28

p=0.00064, χ2 (4) =19.5

		Social worker					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	62.90%	49	-45.90%	12	-24.40%	27
	Unchanged	14.90%	11	55.80%	11	-47.20%	6
	Worsened	-50.40%	20	21.00%	36	29.40%	62

p<0.00001 χ2 (4) >28.5

		Primary care physician					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	73.90%	42	-36.20%	13	-32.20%	22
	Unchanged	22.60%	20	1.70%	14	-17.90%	18
	Worsened	-38.80%	34	15.30%	54	19.30%	89

p<0.00001 χ2 (4) >28.5

		Specialist physician					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	71.80%	40	-8.70%	21	-46.40%	17
	Unchanged	24.60%	16	-21.20%	10	-2.70%	17
	Worsened	-42.40%	27	10.10%	51	23.80%	79

p<0.00001 χ2 (4) >28.5

Anxiety		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	62.00%	42	-13.60%	15	-43.20%	18
	Unchanged	4.20%	18	38.20%	16	-24.30%	16
	Worsened	-28.10%	43	-5.10%	38	25.80%	92

p<0.00001 χ2 (4) >28.5

Anxiety		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	58.10%	41	-31.80%	15	-32.20%	17
	Unchanged	43.90%	23	-18.80%	11	-28.90%	11
	Worsened	-44.10%	28	22.50%	52	25.90%	61

p<0.00001 χ2 (4) >28.5

Anxiety		Speech and language pathologist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	44.10%	39	-27.40%	17	-35.50%	10
	Unchanged	22.00%	19	-18.50%	11	-10.40%	8
	Worsened	-39.00%	24	26.20%	43	28.50%	29

p=0.0004 χ2 (4)=20.5

5 Appendix A: Cross-analyses

Anxiety		Social Worker					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	69.10%	38	-13.70%	14	-48.70%	14
	Unchanged	-8.60%	14	-0.50%	11	7.40%	20
	Worsened	-34.50%	27	7.60%	32	23.80%	62

p<0.00004 χ2 (4) >25.5

Depression		Primary care physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	45.70%	35	-20.40%	16	-21.50%	25
	Unchanged	11.30%	19	12.00%	16	-16.10%	19
	Worsened	-25.30%	38	5.60%	45	15.60%	78

p<0.00958 χ2 (4) >13.4

Depression		Specialist physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	70.40%	40	-23.90%	17	-35.90%	20
	Unchanged	28.40%	18	5.00%	14	-24.90%	14
	Worsened	-46.10%	24	11.00%	47	26.80%	75

p<0.00001 χ2 (4) >28.5

5 Appendix A: Cross-analyses

Depression		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	48.40%	41	-1.90%	17	-39.50%	20
	Unchanged	-11.40%	16	41.20%	16	-12.10%	19
	Worsened	-20.10%	45	-12.30%	31	23.20%	83

p=0.00039, χ2 (4) >20.5

Depression		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	52.20%	39	-14.40%	18	-40.80%	15
	Unchanged	17.60%	18	11.50%	14	-27.30%	11
	Worsened	-33.40%	32	4.00%	41	30.50%	62

p=0.00010, χ2 (4) >23.3

Depression		Speech and language pathologist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	51.40%	41	-22.90%	18	-55.00%	7
	Unchanged	-33.00%	11	48.40%	21	-15.20%	8
	Worsened	-23.30%	28	-4.70%	30	47.70%	31

p=0.00005, χ2 (4) =25

5 Appendix A: Cross-analyses

Depression		Social worker					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	61.30%	38	5.90%	18	-56.30%	12
	Unchanged	-3.80%	14	23.80%	13	-11.50%	15
	Worsened	-34.00%	27	-11.90%	26	36.50%	65

p<0.00001, χ2 (4)>28.5

PTSD		Primary care physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	74.00%	39	-26.50%	13	-41.20%	17
	Unchanged	-24.40%	14	50.60%	22	-12.00%	21
	Worsened	-24.60%	37	-7.00%	36	23.40%	78

p<0.00001, χ2 (4) >28.5

PTSD		Specialist physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	101.10%	42	-40.30%	12	-46.50%	15
	Unchanged	-36.50%	10	38.70%	21	-0.60%	21
	Worsened	-36.30%	27	5.50%	43	23.10%	70

p<0.00001, χ2 (4) >28.5

PTSD		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	77.30%	43	-26.20%	12	-50.90%	14
	Unchanged	-21.00%	15	65.10%	21	-19.30%	18
	Worsened	-27.50%	39	-11.20%	32	29.80%	82

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

PTSD		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	74.30%	43	-28.70%	14	-56.00%	10
	Unchanged	-16.90%	15	46.30%	21	-21.70%	13
	Worsened	-33.80%	30	-2.80%	35	39.10%	58

p<0.00001, χ2 (4) >28.5

PTSD		Speech and language pathologist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	37.70%	36	-19.80%	18	-35.10%	10
	Unchanged	-22.70%	12	27.50%	17	-1.70%	9
	Worsened	-17.50%	30	2.50%	32	26.00%	27

p=0.02784, χ2 (4) =10.9

PTSD		Social worker					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	53.40%	34	5.50%	16	-49.40%	13
	Unchanged	-12.00%	13	48.40%	15	-18.20%	14
	Worsened	-25.70%	29	-21.40%	21	34.90%	61

p=0.00005, χ2 (4) =25

5 Appendix A: Cross-analyses

11. Variation in how **CAREGIVERS' mental health** changed from before COVID-19 pandemic to now, by their **change in access to health professional services.**

Changes in caregivers' mental health (including stress, anxiety, depression, and symptoms from past experiences of traumatic events) varied significantly by their change in access to all types of health professional services (including from primary care physicians, specialist physicians, psychologist and psychotherapeutic service providers, physio- and occupational therapists, speech and language pathologists, and social workers)—with no exceptions. Higher-than-expected proportions of caregivers reported **improved mental health** with **improved access** to each type of health professional service; and **worsened mental health** with **worsened access** to each type of health professional service.

		Primary care physician					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	76.80%	59	-7.70%	61	-25.50%	60
	Unchanged	11.00%	28	16.20%	58	-17.90%	50
	Worsened	-32.90%	58	-1.80%	168	15.10%	240

p<0.00001, χ2 (4) >28.5

		Specialist physician					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	91.80%	55	7.10%	56	-37.50%	50
	Unchanged	19.20%	24	36.20%	50	-30.60%	39
	Worsened	-43.00%	40	-13.30%	111	24.10%	243

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

Stress		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	98.10%	67	-8.00%	44	-37.50%	49
	Unchanged	13.90%	26	42.50%	46	-31.90%	36
	Worsened	-41.10%	52	-7.90%	115	22.60%	251

p<0.00001, χ2 (4) >28.5

Stress		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	118.60%	68	-17.80%	47	-40.70%	39
	Unchanged	16.20%	23	29.20%	47	-33.00%	28
	Worsened	-54.90%	33	-0.30%	134	26.20%	195

p<0.00001, χ2 (4) >28.5

Stress		Social Worker					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	94.50%	43	4.50%	54	-36.10%	41
	Unchanged	39.50%	19	19.40%	38	-29.20%	28
	Worsened	-55.60%	21	-7.70%	102	25.30%	172

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

Anxiety		Primary care physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	80.80%	51	-17.60%	45	-19.30%	55
	Unchanged	20.60%	32	18.70%	61	-23.50%	49
	Worsened	-32.40%	59	0.00%	169	13.40%	239

p=0.00001, χ2 (4) >28.5

Anxiety		Specialist physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	120.50%	53	-5.40%	41	-39.40%	41
	Unchanged	10.40%	23	33.10%	50	-24.90%	44
	Worsened	-43.20%	41	-7.70%	120	20.30%	244

p<0.00001, χ2 (4) >28.5

Anxiety		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	94.60%	55	-11.90%	34	-34.50%	42
	Unchanged	12.90%	29	54.00%	54	-38.20%	36
	Worsened	-33.00%	61	-11.50%	110	21.50%	251

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

Anxiety		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	115.30%	55	-17.60%	38	-40.00%	32
	Unchanged	25.70%	28	24.40%	50	-33.40%	31
	Worsened	-46.80%	40	-1.30%	134	23.50%	194

p<0.00001, χ2 (4) >28.5

Anxiety		Social Worker					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	99.90%	36	7.30%	45	-40.40%	31
	Unchanged	7.00%	16	20.60%	42	-19.00%	35
	Worsened	-38.80%	30	-9.00%	104	20.60%	171

p<0.00001, χ2 (4)>28.5

Depression		Primary care physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	61.40%	45	-15.20%	41	-15.60%	53
	Unchanged	3.60%	37	16.30%	72	-14.20%	69
	Worsened	-25.80%	53	-2.20%	121	13.20%	182

p=0.00008, χ2 (4) =24

Depression		Specialist physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	134.10%	60	-23.10%	32	-37.10%	42
	Unchanged	-6.30%	26	37.80%	62	-21.10%	57
	Worsened	-53.80%	28	-7.50%	91	25.30%	198

p<0.00001, χ2 (4) >28.5

Depression		Psychologist, psychothera-pist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	103.00%	61	-30.00%	26	-30.60%	45
	Unchanged	-23.90%	26	46.90%	62	-15.80%	62
	Worsened	-30.10%	53	-9.30%	85	19.30%	195

p<0.00001, χ2 (4) >28.5

Depression		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	107.10%	55	-21.70%	34	-36.50%	33
	Unchanged	-14.90%	25	41.50%	68	-27.00%	42
	Worsened	-38.80%	38	-10.30%	91	28.40%	156

p<0.00001, χ2 (4) >28.5

Depression		Social Worker					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	90.50%	38	21.60%	50	-49.90%	27
	Unchanged	-14.60%	16	26.90%	49	-15.10%	43
	Worsened	-36.20%	27	-22.10%	68	30.20%	149

p<0.00001, χ2 (4) >28.5

PTSD		Primary care physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	73.80%	47	-18.90%	29	-24.80%	40
	Unchanged	-33.50%	20	25.70%	50	-0.30%	59
	Worsened	-14.80%	57	-3.90%	85	10.20%	145

p=0.00001, χ2 (4) =28.5

PTSD		Specialist physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	141.00%	57	-30.50%	23	-44.50%	29
	Unchanged	-38.00%	16	43.90%	52	-10.60%	51
	Worsened	-42.40%	32	-7.40%	72	23.90%	152

p<0.00001, χ2 (4) >28.5

PTSD		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	113.50%	59	-20.70%	24	-49.10%	26
	Unchanged	-45.50%	17	46.40%	50	-2.90%	56
	Worsened	-25.60%	50	-13.00%	64	21.50%	151

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

PTSD		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	127.10%	61	-24.60%	25	-60.40%	17
	Unchanged	-30.90%	20	53.90%	55	-22.30%	36
	Worsened	-42.60%	34	-15.20%	62	38.30%	131

p<0.00001, χ2 (4) >28.5

PTSD		Social worker					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	57.20%	30	32.90%	46	-49.20%	23
	Unchanged	-23.60%	14	29.50%	43	-12.60%	38
	Worsened	-17.50%	31	-31.10%	47	31.10%	117

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

12. Variation in how **CHILDRENS' mental health** changed from before COVID-19 pandemic to now, by their **change in access to autism- or development-related supports.**

Changes in autistic children's mental health (including stress, anxiety, depression, and symptoms from past experiences of traumatic events) varied significantly by their change in access to different types of autism- or development-related supports and programs (including behavioural therapy services, social skills groups, speech and language therapy, communication supports, and education system supports)— with no exceptions. Higher-than-expected proportions of children were reported to have **improved mental health** with **improved access** to each type of autism- or development-related support; and **worsened mental health** with **worsened access** to each type of autism- or development-related support.

		Behavioural therapy services or programs					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	92.20%	64	-5.70%	43	-39.00%	44
	Unchanged	2.90%	27	69.80%	61	-45.50%	31
	Worsened	-42.80%	42	-22.40%	78	33.90%	213

p<0.00001, χ2 (4) >28.5

		Social skills groups or programs					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	99.50%	58	8.50%	46	-39.90%	49
	Unchanged	4.40%	24	58.10%	53	-31.80%	44
	Worsened	-45.40%	36	-24.00%	73	28.70%	238

p<0.00001, χ2 (4) >28.5

Stress		Speech and language therapy					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	53.10%	51	-2.70%	44	-26.30%	46
	Unchanged	-7.30%	23	48.40%	50	-31.20%	32
	Worsened	-25.70%	46	-17.90%	69	26.70%	147

p<0.00001, χ2 (4) >28.5

Stress		Communication supports					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	76.40%	56	-23.20%	31	-27.10%	40
	Unchanged	-12.10%	20	69.50%	49	-44.10%	22
	Worsened	-41.00%	31	-16.10%	56	35.50%	123

p<0.00001, χ2 (4) >28.5

Stress		Education system accommodations/ supports					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	87.00%	58	-6.00%	42	-33.60%	48
	Unchanged	-8.50%	23	68.30%	61	-38.60%	36
	Worsened	-35.10%	46	-21.60%	80	28.40%	212

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

Anxiety		Behavioural therapy services or programs					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	94.40%	62	6.40%	48	-45.80%	39
	Unchanged	7.80%	24	55.70%	49	-38.30%	31
	Worsened	-43.10%	42	-19.60%	84	31.30%	219

p<0.00001, χ2 (4) >28.5

Anxiety		Social skills groups or programs					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	134.80%	64	4.90%	42	-49.20%	40
	Unchanged	-2.10%	19	85.80%	53	-42.90%	32
	Worsened	-53.20%	32	-26.30%	74	31.80%	260

p<0.00001, χ2 (4) >28.5

Anxiety		Speech and language therapy					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	71.90%	55	-0.30%	44	-36.40%	40
	Unchanged	1.40%	21	50.50%	43	-36.10%	26
	Worsened	-36.80%	40	-16.40%	73	30.20%	162

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

		Communication supports					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	70.30%	52	-19.80%	31	-25.60%	40
	Unchanged	-12.20%	17	59.00%	39	-35.50%	22
	Worsened	-34.70%	36	-9.70%	63	26.70%	123

p<0.00001, χ2 (4) >28.5

		Education system accommodations/ supports					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	84.90%	58	14.50%	50	-46.40%	38
	Unchanged	8.10%	23	62.10%	48	-41.80%	28
	Worsened	-36.70%	49	-22.90%	83	30.30%	228

p<0.00001, χ2 (4) >28.5

		Behavioural therapy services or programs					
Depression	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	100.90%	60	-10.90%	32	-44.30%	33
	Unchanged	-28.70%	23	41.70%	55	-10.90%	57
	Worsened	-37.40%	35	-18.20%	55	29.90%	144

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

		Social skills groups or programs					
Depression	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	116.10%	57	9.20%	35	-50.40%	33
	Unchanged	-12.90%	25	34.80%	47	-11.60%	64
	Worsened	-51.80%	25	-23.90%	48	32.10%	173

p<0.00001, χ2 (4) >28.5

		Speech and language therapy					
Depression	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	78.70%	55	-3.80%	34	-42.50%	31
	Unchanged	-7.00%	26	24.60%	40	-12.10%	43
	Worsened	-45.20%	27	-11.60%	50	33.40%	115

p<0.00001, χ2 (4) >28.5

		Communication supports					
Depression	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	63.80%	51	-12.50%	27	-32.00%	34
	Unchanged	-2.90%	27	52.50%	42	-30.60%	31
	Worsened	-42.30%	26	-23.80%	34	41.00%	102

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

Depression		Education system accommodations/ supports					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	100.50%	57	6.50%	37	-53.30%	27
	Unchanged	-19.80%	26	33.70%	53	-10.50%	59
	Worsened	-39.40%	34	-22.80%	53	33.10%	152

p<0.00001, χ2 (4) >28.5

PTSD		Behavioural therapy services or programs					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	76.10%	52	-16.60%	23	-37.40%	30
	Unchanged	-5.60%	26	43.80%	37	-21.70%	35
	Worsened	-42.80%	28	-14.60%	39	34.80%	107

p<0.00001, χ2 (4) >28.5

PTSD		Social skills groups or programs					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	92.30%	51	12.70%	29	-58.10%	20
	Unchanged	-11.50%	23	42.80%	36	-16.60%	39
	Worsened	-45.20%	26	-30.50%	32	41.60%	121

p<0.00001, χ2 (4) >28.5

		Speech and language therapy					
PTSD	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	57.50%	48	-9.10%	25	-34.90%	28
	Unchanged	-15.20%	22	28.20%	30	-7.20%	34
	Worsened	-29.80%	32	-10.00%	37	27.50%	82

p<0.00001, χ2(4) >28.5

		Communication supports					
PTSD	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	78.60%	55	-10.90%	21	-48.50%	23
	Unchanged	-13.80%	22	48.50%	29	-16.10%	31
	Worsened	-49.60%	21	-21.60%	25	45.70%	88

p<0.00001, χ2 (4) >28.5

		Education system accommodations/ supports					
PTSD	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	76.30%	48	10.30%	28	-48.30%	25
	Unchanged	18.40%	30	35.50%	32	-28.90%	32
	Worsened	-50.40%	25	-23.40%	36	40.70%	126

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

13. Variation in how **CHILDRENS' mental health** changed from before COVID-19 pandemic to now, by their **change in access to health professional services.**

Changes in autistic children's mental health (including stress, anxiety, depression, and symptoms from past experiences of traumatic events) varied significantly by their change in access to all types of health professional services (including from primary care physicians, specialist physicians, psychologist and psychotherapeutic service providers, physio- and occupational therapists, speech and language pathologists, and social workers)—with no exceptions. Higher-than-expected proportions of children were reported to have **improved mental health** with **improved access** to each type of health professional service; and **worsened mental health** with **worsened access** to each type of health professional service.

		Primary care physician					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	90.20%	63	-16.30%	68	-29.90%	39
	Unchanged	-16.40%	22	37.90%	89	-45.70%	24
	Worsened	-33.00%	52	-5.90%	179	28.30%	167

p<0.00001, χ2 (4) >28.5

		Specialist physician					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	75.20%	45	-4.80%	59	-28.00%	42
	Unchanged	11.60%	22	47.20%	70	-55.30%	20
	Worsened	-36.90%	37	-13.70%	122	30.90%	174

p<0.00001, χ2 (4) >28.5

Stress		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	100.10%	62	-12.50%	46	-39.10%	38
	Unchanged	5.70%	24	19.40%	46	-19.10%	37
	Worsened	-42.90%	43	-0.70%	127	21.90%	185

p<0.00001, χ2 (4) >28.5

Stress		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	81.20%	61	-15.40%	40	-31.80%	43
	Unchanged	11.90%	28	19.50%	42	-21.00%	37
	Worsened	-45.00%	37	0.40%	95	23.70%	156

p<0.00001, χ2 (4) >28.5

Stress		Speech and language pathologist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	61.10%	53	-11.60%	44	-24.60%	44
	Unchanged	-18.40%	20	32.20%	49	-17.10%	36
	Worsened	-25.30%	46	-6.60%	87	19.90%	131

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

		Social Worker					
Stress	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	80.90%	56	-18.10%	40	-29.90%	38
	Unchanged	4.60%	22	47.70%	49	-45.70%	20
	Worsened	-40.60%	38	-6.90%	94	29.40%	145

p<0.00001, χ2 (4) >28.5

		Primary care physician					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	79.90%	58	-14.20%	67	-19.30%	39
	Unchanged	8.70%	25	23.80%	69	-23.50%	23
	Worsened	-34.00%	54	-1.10%	196	13.40%	166

p<0.00001, χ2 (4) >28.5

		Specialist physician					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	70.20%	44	-1.70%	60	-29.40%	41
	Unchanged	-1.70%	17	34.70%	55	-35.70%	25
	Worsened	-28.90%	44	-9.00%	133	22.30%	170

p<0.00001, χ2 (4) >28.5

		Psychologist, psychotherapist, counsellor, or therapist					
Anxiety	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	97.30%	60	-17.90%	43	-32.00%	43
	Unchanged	-10.30%	17	25.60%	41	-16.30%	33
	Worsened	-36.10%	49	0.80%	133	16.70%	186

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

Anxiety		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	90.20%	63	-30.20%	33	-24.50%	48
	Unchanged	12.20%	24	34.30%	41	-31.80%	28
	Worsened	-46.70%	37	3.90%	103	21.50%	162

p<0.00001, χ2 (4) >28.5

Anxiety		Speech and language pathologist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	65.50%	53	-8.40%	43	-29.80%	40
	Unchanged	6.10%	23	19.60%	38	-19.60%	31
	Worsened	-34.70%	42	-2.40%	92	21.50%	139

p<0.00001, χ2 (4) >28.5

Anxiety		Social Worker					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	88.70%	58	-19.90%	38	-32.50%	37
	Unchanged	6.80%	19	27.50%	35	-27.60%	23
	Worsened	-42.20%	39	1.80%	106	22.10%	147

p<0.00001, χ2 (4) >28.5

Depression		Primary care physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	98.70%	57	-33.50%	40	-18.00%	37
	Unchanged	-13.70%	29	22.00%	86	-20.60%	42
	Worsened	-39.70%	36	3.70%	130	20.20%	113

p<0.00001, χ2(4)>28.5

5 Appendix A: Cross-analyses

Depression		Specialist physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	77.20%	44	-12.80%	44	-24.60%	39
	Unchanged	-21.30%	20	25.90%	65	-15.00%	45
	Worsened	-29.40%	33	-7.30%	88	21.20%	118

p<0.00001, χ2 (4) >28.5

Depression		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	97.50%	57	-16.70%	37	-36.50%	36
	Unchanged	-12.00%	25	0.60%	44	5.60%	59
	Worsened	-42.80%	33	8.10%	96	15.50%	131

p<0.00001, χ2 (4) >28.5

Depression		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	87.60%	60	-35.10%	26	-25.90%	40
	Unchanged	-25.90%	22	29.10%	48	-6.20%	47
	Worsened	-38.10%	33	4.90%	70	19.00%	107

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

Depression		Speech and language pathologist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	83.10%	54	-13.50%	36	-38.60%	30
	Unchanged	-10.40%	24	5.80%	40	1.40%	45
	Worsened	-47.50%	24	5.40%	68	24.10%	94

p<0.00001, χ2 (4) >28.5

Depression		Social Worker					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	80.00%	54	-13.40%	37	-38.70%	29
	Unchanged	-6.90%	27	23.50%	51	-16.90%	38
	Worsened	-42.30%	30	-5.40%	70	31.70%	108

p<0.00001, χ2 (4) >28.5

PTSD		Primary care physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	66.70%	46	-4.00%	38	-42.30%	23
	Unchanged	-2.10%	26	26.00%	48	-24.40%	29
	Worsened	-34.40%	34	-11.20%	66	35.00%	101

p<0.00001, χ2 (4) >28.5

PTSD		Specialist physician					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	75.20%	40	-6.60%	32	-38.30%	24
	Unchanged	6.30%	23	29.40%	42	-29.50%	26
	Worsened	-42.60%	25	-11.20%	58	34.80%	100

p<0.00001, χ2(4)>28.5

PTSD		Psychologist, psychotherapist, counsellor, or therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	70.20%	46	-20.50%	26	-28.30%	31
	Unchanged	7.00%	25	6.10%	30	-9.00%	34
	Worsened	-41.50%	29	8.30%	65	19.70%	95

p<0.00001, χ2 (4) >28.5

PTSD		Physiotherapist, occupational therapist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	60.30%	46	-18.20%	23	-28.20%	31
	Unchanged	4.60%	27	18.50%	30	-15.10%	33
	Worsened	-39.80%	28	1.00%	46	25.80%	88

p<0.00001, χ2 (4) >28.5

PTSD		Speech and language pathologist					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	67.60%	47	-29.00%	22	-26.30%	28
	Unchanged	-6.40%	23	29.00%	35	-18.90%	27
	Worsened	-40.10%	26	2.30%	49	27.70%	75

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

PTSD		Social Worker					
	% Difference from Expected	Improved	n	Unchanged	n	Worsened	n
	Improved	44.20%	46	-9.10%	29	-30.10%	26
	Unchanged	-6.20%	24	44.60%	37	-32.90%	20
	Worsened	-24.30%	39	-16.50%	43	35.00%	81

p<0.00001, χ2 (4) >28.5

5 Appendix A: Cross-analyses

Variations in how mental health changed from before the COVID-19 pandemic by caregiver autistic status

14. Variation in how **CAREGIVERS' mental health** changed from before COVID-19 pandemic to now, by their **autistic status.**

Changes in caregivers' mental health (including stress, anxiety, depression, and symptoms from past experiences of traumatic events) varied significantly by their autistic status (autistic, non-autistic). Higher-than-expected proportions of **autistic caregivers** reported **improved mental health** (of all types) from before COVID-19 pandemic to now.

Stress		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
	Improved	56.80%	61	-14.60%	129
	Unchanged	-19.70%	24	5.10%	122
	Worsened	-15.80%	86	4.10%	413

p=0.00004, χ2 (2) =20.3

Anxiety		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
	Improved	25.70%	43	-6.80%	120
	Unchanged	1.50%	33	-0.40%	122
	Worsened	-8.90%	95	2.40%	402

p=0.14091, χ2 (2) =3.9

Depression		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
	Improved	34.90%	48	-10.70%	104
	Unchanged	-32.50%	30	9.90%	160
	Worsened	2.30%	91	-0.70%	289

p=0.00264, χ2 (2) =11.9

PTSD		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
	Improved	35.80%	49	-14.90%	74
	Unchanged	-34.20%	27	14.20%	113
	Worsened	1.30%	90	-0.50%	213

p=0.00124, χ2 (2) =13.4

5.c Variations related to the unique experience of autistic caregivers

Variations in caregivers' family situation by caregiver autistic status

15. Variation in caregiver report of **CHILDRENS' level of support needs by caregiver autistic status.**

There was significant variation in children's level of support needs by the autistic status of their caregivers (autistic versus non-autistic). Higher-than-expected proportions of **autistic caregivers** rated their **child's support needs to be at the lowest level** ("requires support").

Child's current support needs		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
	Improved	-75.40%	8	16.30%	175
	Unchanged	-76.00%	9	16.40%	202
	Worsened	60.10%	141	-13.00%	355

p<0.00001, χ2 (2) >23

5 Appendix A: Cross-analyses

16. Variation in **CHILDRENS' age at diagnosis by caregiver autistic status.**

There was significant variation in children's age at diagnosis by the autistic status of their caregivers (autistic versus non-autistic). Higher-than-expected proportions of **autistic caregivers** reported having children **diagnosed at ages 2 to 4 (younger ages);** higher-than-expected proportions of **non-autistic caregivers** reported having children diagnosed at ages **5 to 10 (older ages).**

		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
Age at diagnosis	1	-36.40%	2	7.70%	16
	2	17.50%	32	-3.70%	124
	3	41.60%	47	-8.80%	143
	4	69.20%	52	-14.60%	124
	5	-100.00%	0	21.20%	74
	6-10	-63.50%	12	13.40%	176
	11-17	-17.20%	12	3.60%	71
	18+	-100.00%	0	21.20%	14

$p<0.00001$, $\chi 2$ (2) >35.3

17. Variation in **CAREGIVERS' caregiving situation by caregiver autistic status.**

Caregivers' caregiving situation varied significantly by their autistic status (autistic versus non-autistic). **Higher-than-expected proportions of autistic caregivers reported sharing caregiving responsibilities in non-conventional ways** (with at least one other caregiver who is not considered a parent [e.g., grandparent, other guardian], or with the child's other parent who lives elsewhere [e.g., child spends some nights with their other parent each week]); **lower-than-expected proportions of autistic caregivers reported being a solo parent or sharing caregiving responsibilities in conventional ways** (with the child's other parent who lives in the same house).

5 Appendix A: Cross-analyses

Caregiving situation		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
	I am solely (or almost solely) responsible for the caregiving responsibilities	-13.40%	40	2.50%	252
	I share caregiving responsibilities with at least one other caregiver who is not considered a parent (e.g., grandparent, other guardian)	250.20%	36	-47.00%	29
	I share the caregiving responsibilities with my child(ren)'s other parent(s) who lives elsewhere (e.g., child spends some nights with their other parent(s) each week)	177.60%	36	-33.40%	46
	I share the caregiving responsibilities with my child(ren)'s other parent(s) who lives in the same house	-45.00%	52	8.50%	546

p<0.00001, χ2 (3) >25.9

5 Appendix A: Cross-analyses

18. Variation in **CAREGIVERS' need for respite care at some point** because of COVID-19 pandemic by **caregiver autistic status.**

There was significant variation in caregivers' need for respite care at some point because of COVID-19 pandemic by their autistic status. Higher-than-expected proportions of **autistic caregivers** reported having an increased need for respite at some point because of COVID-19 pandemic, while higher-than-expected proportions of **non-autistic caregivers** reported having no increased need for respite.

Increase in need for respite care		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
	No	-89.60%	3	21.40%	146
	Yes	23.50%	135	-5.60%	432

p<0.00001, χ2 (1) >19.5

19. Variation in **current level of family distress by caregiver autistic status.**

The **current** (at the time of the survey) level of family distress varied significantly by caregiver autistic status (autistic, non-autistic). Higher-than-expected proportions of **autistic caregivers** reported **marked (the highest ratings) levels of family distress** and lower levels of mild distress, currently. There was no significant variation, however, in the level of family distress **experienced at what caregivers' felt was the most stressful part of the COVID-19 pandemic by caregiver autistic status** (p= 0.34612).

Current level of family distress		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
	Mild (1-3)	-20.70%	40	4.90%	222
	Moderate (4-6)	-16.40%	66	3.90%	344
	Marked (7-10)	94.80%	48	-22.60%	80

p<0.00001, χ2 (1) >23

5 Appendix A: Cross-analyses

Variations in caregivers' economic situation by autistic status

20. Variation in **CAREGIVERS' employment status** at any time since the start of the COVID-19 pandemic **by caregiver autistic status.**

Caregivers' **employment status** at any time since the start of the COVID-19 pandemic (March 2020) varied significantly by their autistic status. Higher-than-expected proportions of **autistic caregivers** reported **being employed** at any time since the start of the COVID-19 pandemic; higher-than-expected proportions of **non-autistic caregivers** reported **NOT being employed** at any time since the start of the COVID-19 pandemic.

Employed at any time since the start of the COVID-19 pandemic		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
	No	-59.30%	18	13.70%	218
	Yes	20.30%	155	-4.70%	533

p<0.00001, χ2(1) >19.5

21. Variation in CAREGIVERS' **change in level of employment** from before the COVID-19 pandemic by **caregiver autistic status.**

Caregivers' change in level of employment (hours worked) from before the COVID-19 pandemic varied significantly by their autistic status. Higher-than-expected proportions of **autistic caregivers** reported changes (both increases and decreases) to their levels of employment compared to their non-autistic counterparts.

Change in level of employment from before the COVID-19 pandemic		Autistic Status			
	% Difference from Expected	Autisic	n	Not Autistic	n
	Increased	18.20%	54	-5.50%	144
	Unchanged	-30.10%	45	9.00%	234
	Decreased	25.80%	54	-7.70%	132

p=0.00132, χ2 (2) =13.3

5 Appendix A: Cross-analyses

22. Variation in **CAREGIVERS' change in personal income** from before the COVID-19 pandemic by **caregiver autistic status.**

Caregivers' **change in personal income** from before the COVID-19 pandemic varied significantly by their autistic status. Higher-than-expected proportions of **autistic caregivers** reported changes (both increases and decreases) to their income compared to their non-autistic counterparts.

		Autistic Status			
Change in income from before COVID pandemic	% Difference from Expected	Autisic	n	Not Autistic	n
	Increased	13.00%	63	-25.20%	61
	Unchanged	-26.80%	40	32.70%	106
	Decreased	12.70%	66	-6.50%	80

p=0.00005, χ2 (4) =25

6 Appendix B: Lessons learned from strengths and limitations of the survey

Survey strengths

We suggest the following strengths of this survey (including aspects of the development, design, implementation, analysis and reporting) are worthwhile to consider including in future surveys of autistic people and their caregivers:

1. Engagement of the autism community at several levels was done to promote relevance, credibility, and usefulness of the survey and its findings for the different audiences across this community. For our survey this included:
    a. Attending to the composition of the survey leadership to ensure autistic and caregiver representation.
    b. Recruiting a mixed group of twenty autistic adults and caregivers to comment on the content and design of the survey and its report.
    c. Inviting and involving a total of seventeen provincial, territorial, and other autism-focussed organizations in the development and dissemination of the survey and its report.

Some of the realized and potential benefits include sharing of information about existing survey efforts (including methods), broader distribution and reach, and wider uptake of results by organizations providing services to the autism community. While time-consuming, we hope such a community-based approach represents a sustainable model for conducting national autism surveys on topics of importance to the autism community in future years.

2. Some demographic questions were developed to be comparable with Canada Census data, allowing for comparisons to the Canadian population for reference purposes (but not to facilitate judgments of representativeness). While we tailored many questions based on feedback from autistic people and their caregivers, we suggest that it is important for developers of tailored autism-related surveys to be familiar with Statistics Canada equivalent questions to allow for comparisons that may be of interest.
3. We asked caregivers to answer questions about individual autistic children (rather than multiple autistic children they may have under their care), with the option to provide information for up to three autistic children, which ensured that child data collected corresponded to individual children. This allows for true child-level analyses (rather than being limited to caregiver-level analyses of experiences with their autistic child or children, which are not child-specific). It also satisfies the preference we have heard from caregivers, who want to be able to provide unique information about children under their care.
4. Comprehensive results of the survey have been made available to the broader autistic community via this report, which is important to help maximize the survey's utility. Community access to autism survey results is important because of the usefulness and interest they have for multiple users, including the broader public, autistic people and their families, researchers, provincial and territorial autism organizations, service providers and educators, and policy-makers. The more widely available that findings about the autism community can be, the more benefit and value they have.

6 Appendix B: Lessons learned from strengths and limitations of the survey

Questions for future surveys

Some additional questions could have provided information that in hindsight may have been useful. For caregivers, it would have been helpful to know more about the speaking level and autonomy of children being reported on, especially adult children. We would therefore consider adding questions about the child such as the following in future surveys:

1. What is this child's speaking level (e.g., speaking vs. non-speaking/minimally speaking)?
2. For adult-aged children only: Do you think this child could complete this survey on their own?
3. For adult-aged children only: If yes to the above, did they also complete this survey?

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Lessons from survey limitations: Reductions to valid response rates

Apart from the 1,334 valid respondents (i.e., survey records) to the survey, 986 additional respondents were removed for providing *incomplete information* or being *fraudulent*.

1. Learnings from the effects of incomplete responses:

We removed 504 records (respondents) for being *incomplete*, defined as not completing any of the survey's content questions, which came after a set of forced-response demographics questions ("prefer not to say" was an option for demographics questions). Of these, 191 did not answer any demographic questions, suggesting they may have been simply exploring the survey link. The remaining 313 who answered varying numbers of demographics likely discontinued the survey for other reasons, one of which could have been participants feeling they had insufficient time to continue, given the survey length. We discuss this further under *Recommendations to maximize valid response rates.*

2. Learnings from the effects of fraudulent responses:

We removed 482 records (respondents) for being fraudulent. A key reason for this fraud is to access compensation that is offered in research. Thus, a key reason for fraudulent actors to complete the PANCAN Autism Survey was likely an attempt to qualify to enter the random draw at the end of the survey to receive one of the limited number of $50 gift cards being offered. Records were classified as fraudulent if they met multiple (two or more, and usually three or more) criteria suggesting the respondent could be fraudulent, and the combination of criteria for excluding records was agreed upon by at least 2 raters to positively identify fraud with high certainty and have a low chance of including valid responses. We do not list the criteria here to avoid sharing information that could be used by fraudulent actors to interfere with survey validity in the future.

We note, however, that responses to qualitative questions in our survey provided useful clues about respondents that used artificial intelligence to generate text responses (often such responses failed to answer the question from the correct perspective, or had other identifying patterns). Additionally, many fraudulent responses tended to be clustered in time, within events lasting one to three hours.

Fraud is increasingly recognized by the research community internationally as a threat to the validity of autism surveys and internet research in general, especially since advent of accessible artificial intelligence technology (e.g., bots) *(see https://www.thetransmitter.org/ethics/scammers-threaten-quality-of-research-survey-data/?fspec=1&swcfpc=1, and https://journals.sagepub.com/doi/10.1177/13623613231174543).*

The ratio of fraudulent records to valid records in our survey (482:1334, or 36%), was lower than for another national autism-related survey conducted just prior to the 2023 PANCAN Autism Survey (roughly 5:1, or 500%). A difference with the prior survey was its offer of universal compensation (all respondents received financial compensation). This difference suggests reducing the probability of receiving compensation via the random draw was a worthwhile strategy to reduce the extent of fraud. We also included a warning within the survey consent information to discourage fraud.

Nevertheless, fraud was still a problem in the PANCAN Autism Survey. While we believe the rate is small, the final set of respondents included in the analysis may still have contained some that were fraudulent. The effect this had on the final data and analysis may be reduced by the fact that content questions were optional, so that some of the fraudulent respondents that were not removed may have skipped answering them to reach the draw entry at the end.

Recommendations to maximize valid response rates

To further minimize fraudulent response rates and maximize valid response rates in future surveys, we recommend the following:

1. Remove financial incentives (compensation) altogether
2. Limit survey length to 10 minutes, especially given that no compensation is offered
3. Involve autistic adults and caregivers in identifying and prioritizing the survey topics (e.g., targets for change) that are relevant to them
4. Consider planning multiple surveys on discrete topics to keep length of individual surveys short

We base these recommendations partly on our anecdotal experience that long surveys represent a burden that is a barrier to participation for some caregivers and autistic adults; meanwhile, also in our experience from past research, autistic adults and caregivers are generally motivated to share their perspectives and experience in research when the aim is to inform the policies, services and supports that affect them.