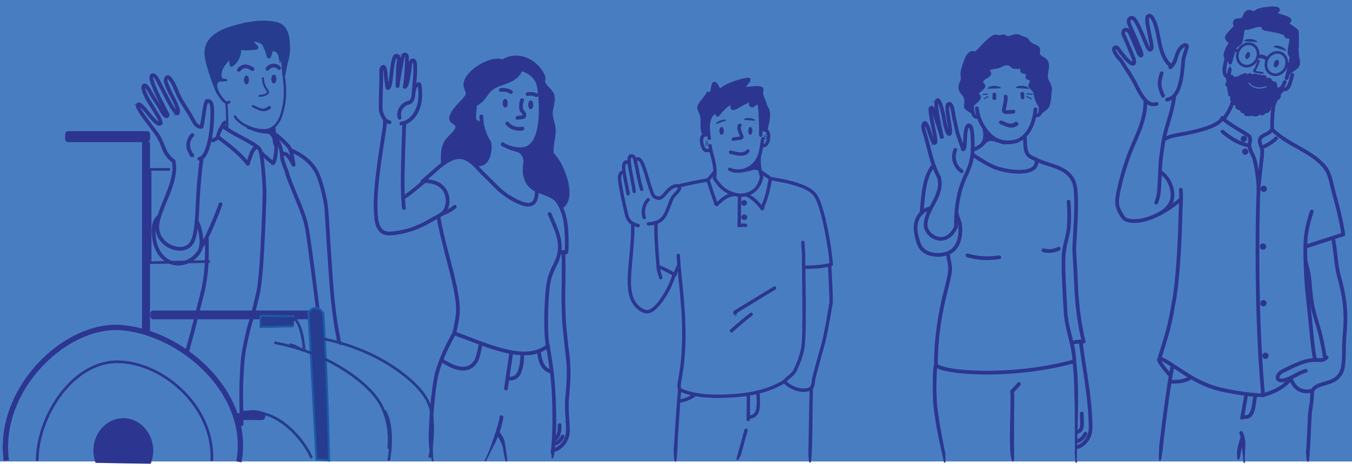
Evolving impacts of the COVID-19 pandemic on autistic people and their caregivers:

Key findings from the 2023 Pandemic Canadian Autism Needs Assessment Survey



Community 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

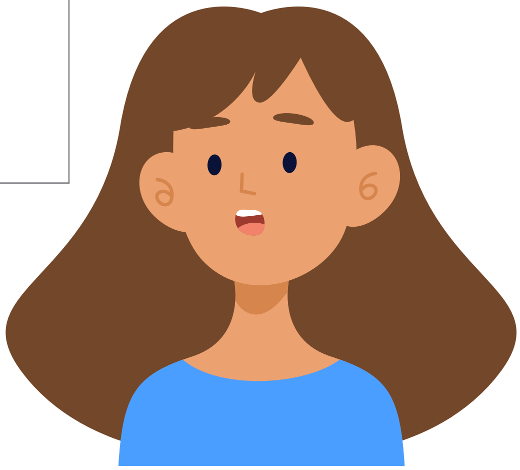
1 Introduction

The aim 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. This included understanding the impacts on their experiences of services and supports. This survey 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 with the participation of seventeen provincial, territorial, and other autism-focussed organizations across Canada.

This report highlights four key findings from the survey. It does not provide the full results.

A comprehensive report of survey results, which includes more detail about the findings, can be found at autismspeaks.ca/2023PanCan/ or you can scan the QR code here.

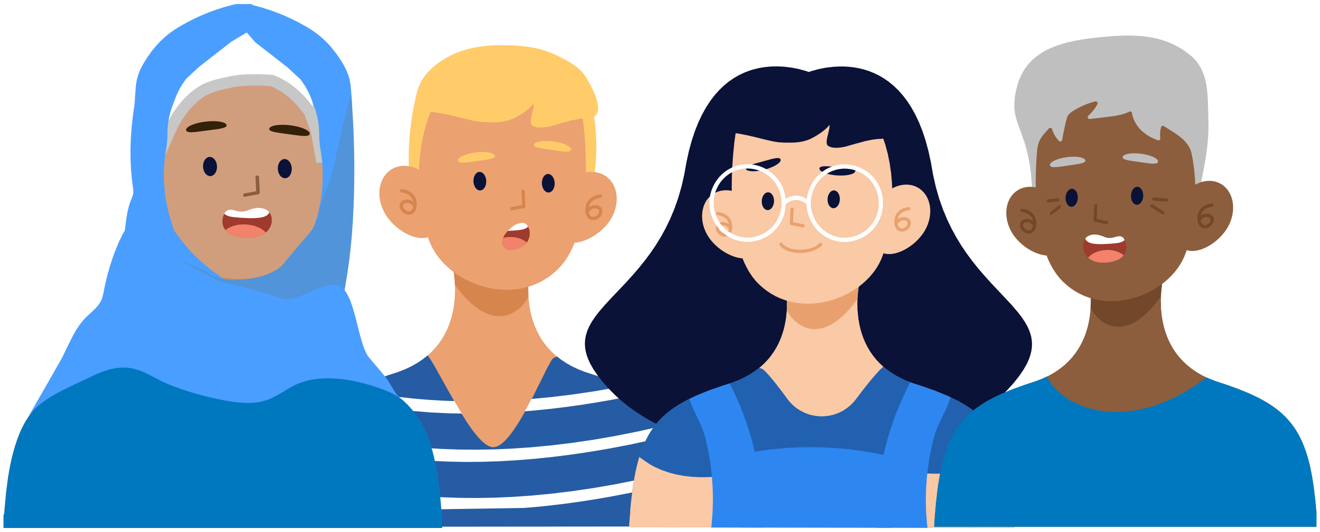
***A note about language:** The developers of this report respect that different people have different preferences for identity-first ("autistic person") versus person-first ("person with autism") language for referring to autistic people. For consistency, we decided to use identity-first language throughout 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.



2 About the respondents

The respondents to the survey included 448 autistic adults and 1,082 caregivers of one or more autistic children of any age (196 of these identified as *both* an autistic adult and a caregiver). Caregivers reported on 975 autistic children currently under their care. About one quarter of autistic children reported on were adult aged (23% were 18+ years). For more details about the characteristics of survey respondents and children reported on, please refer to the comprehensive report.

The people reported on in this survey are only a small proportion of all the autistic adults, caregivers, and autistic children living in Canada. Also, the respondents to this survey were not selected in a way that would make them representative of the overall population. It is therefore important to be careful about using these results to make conclusions about the overall populations of autistic adults, caregivers, and autistic children in Canada.



3

Key Finding #1

Changes in access to services and supports were generally accompanied by changes to health. Importantly,worse access meant 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 health 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.

The check marks in the three tables below show how consistent this was. The few exceptions are shown below in the boxes with an “X”.

✓ Significant variation in changes to health with changes to access (and a relationship of worsened health with worsened access, improved health with improved access)

✗ No significant variation in changes to health with changes to access

4

Key Finding #1

Autistic Adults

	General Health	Stress	Anxiety	Depression	Symptoms from experiences of past traumatic events
Housing supports	✓	✓	✓	✓	✓
Employment supports	✓	✓	✓	✓	✓
Postsecondary education supports	✓	✓	✓	✗	✗
Communication supports	✓	✓	✓	✓	✗
Peer support programs	✓	✓	✗	✗	✗
Financial supports	✓	✓	✓	✓	✓
Primary care physician	✓	✓	✓	✓	✓
Specialist physician	✓	✓	✓	✓	✓
Psychologist, psychotherapist, counsellor, or therapist	✓	✓	✓	✓	✓
Physiotherapist, occupational therapist	✓	✓	✓	✓	✓
Speech and language pathologist	✗	✓	✓	✓	✗
Social worker	✓	✓	✓	✓	✓

5

Key Finding #1

Caregivers

	General Health	Stress	Anxiety	Depression	Symptoms from experiences of past traumatic events
Primary care physician	✓	✓	✓	✓	✓
Specialist physician	✓	✓	✓	✓	✓
Psychologist, psychotherapist, counsellor, or therapist	✓	✓	✓	✓	✓
Physiotherapist, occupational therapist	✓	✓	✓	✓	✓
Social worker	✓	✓	✓	✓	✓

6

Key Finding #1

Autistic Children

	General Health	Stress	Anxiety	Depression	Symptoms from experiences of past traumatic events
Primary care physician	✓	✓	✓	✓	✓
Specialist physician	✓	✓	✓	✓	✓
Psychologist, psychotherapist, counsellor, or therapist	✓	✓	✓	✓	✓
Physiotherapist, occupational therapist	✓	✓	✓	✓	✓
Social worker	✓	✓	✓	✓	✓
Behavioural therapy services or programs	✓	✓	✓	✓	✓
Social skills groups or programs	✓	✓	✓	✓	✓
Speech and language therapy	✓	✓	✓	✓	✓
Communication supports	✓	✓	✓	✓	✓
Education system accommodations or supports	✓	✓	✓	✓	✓

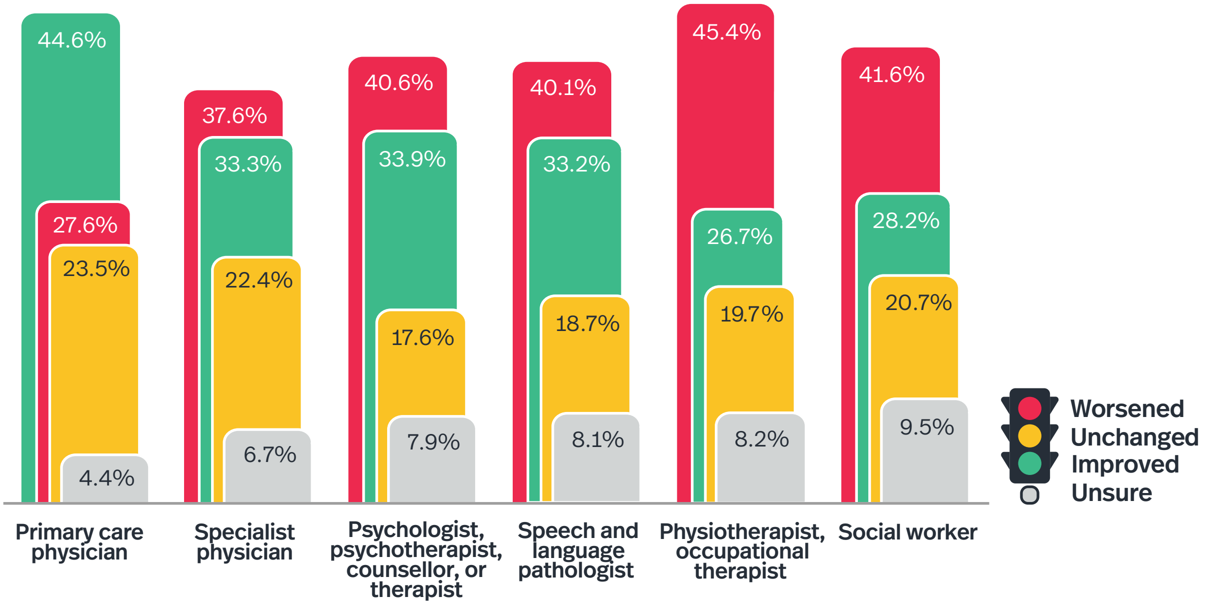
7

Key Finding #2

Remote delivery of many health professional services was more acceptable for meeting autistic adult and caregiver needs, but less acceptable for meeting autistic children's needs.

Remote or virtual delivery (rather than in-person delivery) of most health professional services during the COVID-19 pandemic was more often seen by respondents as a good thing for meeting autistic adults' and caregivers' health needs (increased accessibility, more happiness; for graphs, please see the comprehensive report). But remote delivery for meeting autistic children's health needs was more often reported on negatively by their caregivers' (more unhappiness; see graph below). 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.

Happiness with health professional services for autistic children being available via remote delivery



8

Key Finding #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.

For overall child development, caregivers were asked to consider their child's rate of developing physical abilities, language abilities, and daily living skills in the home. Caregivers were asked to indicate their certainty of whether this development slowed, or did not slow, because of the COVID-19 pandemic—including because of closures, restrictions, policies or other pandemic-related changes.

9

Key Finding #4

Autistic caregivers were likely to have experienced the COVID-19 pandemic differently than non-autistic caregivers, in several different ways.

For example, autistic caregiver respondents were more likely to have:

- 😐 Shared child caregiving responsibilities in non-conventional ways, such as with another caregiver who is not a parent, at the time of the survey
- ☹ Experienced higher levels of unmet needs for health professional services for their own care at the time of the survey
- ☹ Had an increased need for respite care at some point because of the pandemic (including because of closures, restrictions, policies or other pandemic-related changes)
- ☹ Experienced high levels of family distress needing crisis supports at the time of the survey
- 🙂 Reported improvements to mental health over the course of the pandemic (the explanations for this were not studied)

10 Acknowledgements

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 Family Autism 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, Jonathan Lai, Deepa Singal, Stelios Georgiades, Lena Trubnikova, Kathi Cosgrove, Stephen Gentles, Nevart Terzian, Daniel Grant, Mathieu Giroux, and Jill Farber; 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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For those wishing to reference findings from this report, we suggest referring to the original comprehensive report, can be found at autismspeaks.ca/2023PanCan/ or you can scan the QR code here.

The recommended citation is available within the comprehensive report.