MacART | McMaster Autism Research Team
Advancing autism care through meaningful research

autism speaks CANADA

CASDA ACTSA

PanCANS SURVEY

Caregivers of children with ASD and advocates/autistic adults across Canada participated in the Pandemic Canadian Autism Needs Assessment Survey (PanCANS) between May 13–24, 2020. Respondents shared their experiences to help inform on the impacts of the COVID-19 pandemic.

DEMOGRAPHICS

1,066 responses

- **1,001** in English
- **65** in French

We asked respondents if they identified as being on the spectrum, and if they were completing the survey as a caregiver (parent/guardian/family member) or as an advocate (questions about themselves).

- Caregivers (79%)
- Both a caregiver + on the spectrum (15%)
- On the autism spectrum (8%)

The majority of caregivers described themselves as:

- Caring for children ages 5–17: 79%
- Mothers: 85%

Every province was represented, as well as the Yukon + Northwest territories.

Ontario had the highest response rate.

Only Nunavut was not represented.

SIZE OF HOUSEHOLDS

- 2% lived with no other people
- 10% lived in a household of two
- 21% lived in a household of three
- 34% lived in a household of four

ADDITIONAL DIAGNOSES

Of those surveyed, the following additional diagnoses and/or conditions were listed as most common:

- Anxiety
- Attention Problems
- Sleep Problems
- Gastrointestinal Problems

It's important to note other conditions not listed in the survey, such as OCD, were also common.

Caregivers were asked if the individual(s) they were caring for had any of the co-existing diagnoses. The following were most common:

- Anxiety
- Attention Problems
- Behaviour Problems
- Sleep Problems
- Intellectual Disability

INDIVIDUAL & FAMILY HEALTH

42% of respondents identified feeling "very stressed" due to COVID-19 (vs. manageable, minimal and no stress)

61% identified feeling concerned, very or extremely concerned that they or a family member have caught/would catch COVID-19 (vs. somewhat to no concern)

24% of respondents felt they were coping poorly to very poorly with the changes related to COVID-19 (vs. okay, well and very well)

REDUCING EXPOSURE

The following were identified as the most difficult measures for families to reduce potential exposure to COVID-19 in their household:

- Taking advantage of special opening hours for people with disabilities or their caregivers
- Requesting assistance from families, friends or others to access crowded environments
- Avoiding touching of eyes, nose and mouth
- Gathering urgent items to reduce access to public places e.g.: food, cleaning supplies, medications
- Self-isolating

TOP FACTORS PREVENTING PHYSICAL DISTANCING

- Getting food/groceries
- Need to earn income
- Getting physical activity

COPING & RESILIENCE

The most difficult measures identified in increasing coping and resilience in the household were noted to be:

- Maintaining personal + familiar routines or creating new ones
- Providing engaging + age appropriate activities
- Encouraging children to play + socialize with others in the household
- Maintaining a healthy lifestyle (e.g. regular sleep, exercise, healthy eating)
- Engaging in activities that are enjoyable + relaxing
- Stay connected + maintaining social networks via telephone, social media, video conference

COVID-19 was identified as negatively impacting the following areas:

CAREGIVERS:

- Education and learning
- Behaviour
- Relationship with family and friends
- Emotional and mental health

44% of caregivers reported their family was coping "somewhat well" to "very well" with the day-to-day demands amidst changes related to COVID-19

ADVOCATES:

- Emotional and mental health
- Sleep
- Physical health
- Relationship with family and friends

41% of advocates reported they were coping "somewhat well" to "not well at all" with the day-to-day demands amidst changes related to COVID-19

The top feelings identified during the COVID-19 pandemic are:

	Caregivers	Advocates
1	Stress	Anxiousness
2	Worry	Stress
3	Anxiousness	Worry
4	Isolation	Isolation
5	More pressure for daily tasks	More pressure for daily tasks

IMPACT OF THE COVID-19 PANDEMIC

12% of respondents had been tested for COVID-19.

Top ways families and advocates have been affected by COVID-19:

CAREGIVERS:

- Child's school/daycare has been closed
- Homeschooling children
- Accessing food, home essentials and medication
- Earnings/income has decreased

ADVOCATES:

These were identical to caregivers.

- Accessing food, home essentials and medication
- City under a mandatory lockdown
- Search for employment is more challenging than before
- My school/day program has been closed

Of those working from home or with their child's school / daycare / day programming closed, the hardest activities for families to do were:

- Providing homeschooling and physical activity
- Maintaining calm and reducing stress
- Minimizing bad behaviours + encouraging good ones
- Establishing routines and schedules

CHILDREN'S UNDERSTANDING OF COVID-19

- Completely (7%)
- Moderately well (19%)
- Moderately (16%)
- Somewhat (25%)
- Not at all (33%)
- No response (2%)

The majority (31%) of respondents selected "not at all" (versus completely, moderately well, moderately, and somewhat) about whether their child with ASD understood about information and changes related to COVID-19.

The most challenging areas related to COVID-19 involved:

- Accessing behavioural health services (ABA, psychological support, or care)
- Lack of social engagement
- Accessing peer-to-peer support
- Financial challenges
- Mental health concerns (high stress, anxiety, OCD, depression)

What activities did respondents engage in during the pandemic?

CAREGIVERS:

- Stopped physical attending school/daycare/day program
- Paid closer attention to physical health symptoms
- Increased hygiene protocols (washing hands, avoid touching face)
- Stopped travelling outside of the city they reside in
- Avoided leaving home

ADVOCATES:

- Increased hygiene protocols (washing hands, avoid touching face)
- Avoided crowded places (malls, grocery stores)
- Avoided leaving home
- Paid closer attention to physical health symptoms

SERVICE ACCESS

Respondents were asked to rank the difficulties their family was experiencing in supporting their children with ASD during COVID-19.

MOST CHALLENGING:

1. Accessing behavioural health services (ABA, psychological support/care)
2. Accessing peer to peer support
3. Mental health concerns (high stress, anxiety, OCD, depression)

LEAST CHALLENGING:

1. Accessing groceries and essentials
2. Accessing online curated resources and information
3. Financial challenges

Respondents were asked what information, services, and supports they needed to access over the last month preceding the survey.

✓ ADEQUATE ACCESS:

- Relevant information about COVID-19: 635 / 1066 (60%)
- Flexible work-from-home arrangements: 378 / 1066 (35%)
- Accessible information for children about COVID-19: 344 / 1066 (32%)

✗ NO ACCESS:

- Ask questions, raise concerns with government: 619 / 1066 (58%)
- Financial compensation to take time off work: 594 / 1066 (56%)
- Help and support from the community and family: 572 / 1066 (54%)
- Tax relief or subsidy related to COVID-19: 551 / 1066 (52%)

What supports were being accessed at the time of the survey?

CAREGIVERS:

- Education plans (40%)
- Financial support related to COVID-19 (26%)
- Access to health professionals (24%)
- Virtual intervention (24%)

ADVOCATES:

- Peer and family support (39%)
- Access to health professionals (29%)
- Financial support related to COVID-19 (23%)
- Virtual peer support groups (20%)

SERVICE NEEDS & GAPS

What supports were respondents not accessing but would have been useful at the time? Those rated the highest:

CAREGIVERS:

- Recreational programs/products
- Flexibility in using government funding
- Financial support
- Mental health supports
- An ASD-specific hotline
- Peer and family support

ADVOCATES:

- Recreational programs/products
- An ASD-specific hotline
- Financial support
- Access to health professionals
- Mental health supports

THANK YOU to all who took the time to share their views with us.