FAMILIES IN FLUX

FINDINGS FROM THE 2021 ONTARIO AUTISM CAREGIVER SURVEY ON EDUCATION, SERVICE ACCESS AND WELL-BEING IN THE CONTEXT OF COVID-19

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LARC
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Research Consortium

Autism ONTARIO

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LARC
Laurier Autism
Research Consortium

Founded by Drs. Janet McLaughlin and Margaret Schneider the Laurier Autism Research Consortium (LARC) is a passionate group of professors, research assistants and students, working alongside various autism organizations, clinical experts, parent advocates, families and autistic individuals. Through conducting and sharing socially engaged research with policymakers and the public, our collective goal is to improve service access and quality of life for all autistic people and their families.

AutismONTARIO

MISSION
CREATING A SUPPORTIVE AND INCLUSIVE ONTARIO FOR AUTISM

VISION
BEST LIFE, BETTER WORLD, MAKING AUTISM MATTER

OUR VALUES

C COLLABORATION
We believe in the power of working side by side with individuals, families and communities to make informed choices about autism.

A ACCOUNTABILITY
We hold ourselves and others responsible to achieve successful outcomes through high standards of integrity and fiscal responsibility.

R RESPECT
We value equity, diversity and inclusion, and we listen to understand.

E EVIDENCE INFORMED
We use and create knowledge to guide our decisions and work.

ENDS
BECAUSE AUTISM ONTARIO EXISTS:

Individuals and families in their communities are equitably and seamlessly supported across their life course.

Individuals, families and communities have meaningful: Supports, information and connections.

Information/knowledge is created, curated and mobilized that is: Trustworthy, timely and relevant.

CAREGIVER
EXPERIENCES
WITH COVID 19

EXECUTIVE SUMMARY

The 2021 LARC- Autism Ontario Caregiver Survey was conducted as a partnership between the Laurier Autism Research Consortium (LARC) and Autism Ontario.

The purpose of the survey was to gather information from primary caregivers of Ontario children or youth with an autism diagnosis (aged 1-17 years) about their recent experiences in the context of the COVID-19 pandemic. Topics included: a) Child education, b) Autism services and supports, c) Child recreation, and d) Caregiver well-being.

The survey was available online in English and French, from June 30 to July 23, 2021, and caregivers could complete questions for up to three children with an autism diagnosis. A total of 2,685 Ontario caregivers completed questions about their child(ren) or youth with an autism diagnosis, reporting on a total of 2,933 children. Approximately 13% of caregivers reported having multiple children with an autism diagnosis.

Most caregiver respondents were female (90.4%). Only 2.8% indicated they spoke French most often at home, while 13.7% spoke a language other than English or French; and 38.1% were not Canadian citizens by birth. Of the children reported on, 75% were male, and 10% were not yet school-aged.

A small proportion (3.3%) of children were school-aged but unregistered in any school for the 2020-2021 school year; the most common reason given for the child not being registered was a sense that the education system could not offer the accommodations needed.

I. CHILD EDUCATION

Following the first COVID-19–related school shutdown from March-June 2020, caregivers reported that 69% of their children with an autism diagnosis transitioned directly back to in-person schooling in fall 2020. Educational programming received by children in place of in-person learning during fall 2020 included remote learning with the child’s school (83%), therapy (8%), homeschool (7%), or other private learning arrangements (2%).

During the January and April 2021 province-wide school shutdowns (duration of the January 2021 shutdown varied by public health region; the April shutdown lasted from April 19 to the summer break), some children with special education needs were provided with in-person education. Caregivers with children registered in school indicated that 11% of children attended in-person school during both shutdowns, 42% engaged in remote learning only, and 27% participated in a mix of in-person and remote learning; meanwhile, 20% of children participated in neither in-person nor remote learning at some point during the shutdowns.

> *58% of children were reported to be poorly or not engaged in online learning.*

Among children who did neither in-person nor remote learning during the January and April 2021 province-wide school shutdowns, caregivers reported 40% of children not being offered in-person learning, while for 69% of children remote learning was reported to "not work" (or to be ineffective). When asked to expand, many caregivers shared comments suggesting that in-person learning would have been needed or helpful to keep their child in school.

Caregivers reported that 8% of children who participated in remote learning did not have sufficient access to the technology needed to support online learning during the 2021 school shutdowns.

Meanwhile, 58% of children were reported to be poorly or not engaged in online learning; this varied by age to an extent that was statistically significant, with children aged nine years or less tending to have higher rates of poor engagement. Regarding the level of overall satisfaction with their specific child's educational experience during the 2021 COVID-19 school shutdowns, 47.4% of caregivers reported being dissatisfied or very dissatisfied, with 18.4% neither satisfied nor dissatisfied, and 34.2% satisfied or very satisfied; this varied by racial/ethnic identification to an extent that was statistically significant, with only 30% of racialized caregivers responding that they were satisfied or very satisfied compared to 38% of white caregivers.

Many caregivers reported negative impacts of the April 2021 province-wide shutdowns on their child in the areas of mental health (50% of children), physical health (40% of children), social functioning (67% of children), and overall development (54% of children). Despite the option for some children with special education needs to attend school in-person during the province-wide shutdowns, overall, parents estimated high rates of in-person school missed, with 32% missing 5-20 weeks, and 26% missing over 20 weeks. As an indication of caregivers' positive experiences of educators' efforts during the shutdowns, 76% felt that their child's educators acknowledged their concerns or requests over the school year.

Finally, school exclusions, (children sent home) stemming from schools not having the proper supports to manage issues related to the child's behaviour or safety, were reported for 23% of students over the school year.

II. AUTISM SERVICES, SUPPORTS & RECREATION

Regarding the form of Ontario Autism Program (OAP) benefits received, 65% of caregivers reported receiving direct funding (Childhood Budget or Interim One-Time Funding), while 5% received behaviour plans through the "legacy" (former) program, 13% received other OAP benefits (Service Navigation, Foundational Family Services, March 2021 OAP pilot program), and 16% reported receiving no OAP benefits in the previous 12 months.

A majority of caregivers (53%) reported that the OAP met their child's therapy and support needs to a low extent or not at all in the preceding 12 months. Among caregivers who expanded on this, many mentioned that their child needed supports or services that were not funded. The OAP was rated as beneficial to their child's life by 78% of caregivers. When asked to expand, some of the caregivers mentioned that funded therapies and services made a positive difference that could not have been achieved otherwise, and others remarked that the available funding was insufficient to cover necessary expenses.

The OAP was rated as beneficial to their child's life by 78% of caregivers.

When asked to indicate the importance of including different features in provincially funded autism services, a needs-based approach was most highly endorsed, followed by minimal wait-times, a strengths-based approach, family-centred care, integrated care, caregiver support, and remote service provision.

There were substantial losses to children's recreational programming and unstructured social activities when comparing pre–COVID-19 rates of participation. For example, 65% of caregivers reported their child participating in visits from family before COVID-19, whereas only 43% reported participation in in-person family visits during the COVID-19 pandemic. Child physical activity levels were also much reduced. The proportion of children getting six or more hours of physical activity per week during the pandemic (45%) was far lower when compared to before (70%).

III. CAREGIVER WELL-BEING

Caregivers reported spending an average of 5.9 hours per week advocating, and 9.3 hours per week navigating care for their child(ren) with an autism diagnosis (a total of 15.2 hours). When asked to expand, many caregivers mentioned that this represents a considerable amount of work that burdens parents and contributes to stress.

Regarding caregiver well-being, a high proportion reported their current level of stress as moderately high (56%), while 8% reported a marked level of stress (approaching or in crisis). When asked to expand, caregivers mentioned multiple demands, such as combined childcare and work, and demands related to navigation and availability of autism-related care, as important sources of stress. As a result of COVID-19, caregiver mental health worsened for 69%, with some expanding further to say that working from home was a factor.

As a result of COVID-19, caregiver mental health worsened for 69% of respondents.

It is, however, interesting to note that mental health was reported to have improved for 10% of caregivers, with some expanding further to say that their mental health had improved later in the pandemic. For reference, this survey was conducted in the early to mid-summer of 2021, when some of the restrictions had eased, so it is possible that any reported improvement could be reflective of the change in available supports during this point in time.

Sixty percent of caregivers indicated that their mental health had been very or extremely affected by the challenges of accessing and navigating autism-related care; and 48% indicated that their physical health was very or extremely affected by the challenges of accessing and navigating autism-related care.

Of those who commented further on their mental and physical health problems, parents described anxiety-related mental health concerns, and a lack of capacity (time or energy) for physical self-care, leading to declines in physical health.

INTRODUCTION

This 2021 Ontario Caregiver Survey was conducted as a partnership between the Laurier Autism Research Consortium (LARC) and Autism Ontario. This survey was developed partly as a follow-up to two previous caregiver surveys: the 2019 LARC Autism Services in Ontario Survey[1] and the 2020 Autism Ontario Education Survey[2].

The purpose of this survey was to gather information from primary caregivers of Ontario children or youth with an autism diagnosis aged 17 years or younger about their recent experiences in the context of the COVID-19 pandemic regarding the following topics:

I. Child Education
II. Autism Services, Supports & Recreation
III. Caregiver Well-Being

LARC researchers and Autism Ontario developed the survey questionnaire with feedback from partners and community stakeholders, including parents of children with an autism diagnosis, adult Autistic self-advocates, and professionals. Stakeholders were chosen for their expertise and understanding of issues that broadly affect members of the groups they identify with, including Indigenous and immigrant communities.

> *12.7% of caregivers said they had more than one child with an autism diagnosis*

Their input was used to increase sensitivity and appropriateness of survey questions to the needs, considerations, and perspectives of varying groups in the autism community. The survey was distributed as widely as possible across Ontario, as an openly available link, through Autism Ontario channels and with the help of numerous partner organizations. The survey was available online only, in English and French, from June 30 to July 23, 2021. Caregivers with other language needs were offered interpretation support.

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[1] *McLaughlin, J., & Schneider, M. (2019). Autism Services in Ontario: Impacts on Family and Child Well-Being. Laurier Autism Research Consortium (LARC). Retrieved from https://www.wlu.ca/academics/faculties/faculty-of-human-and-social-sciences/faculty-profiles/janet-mclaughlin/larc/assets/documents/larc-report.pdf*

[2] *Gentles, S. J., White, C., Murphy, S., Cnudde, M., Bethel, J., & Spoelstra, M. (2020). Readiness for the Safe and Successful Return to School: Findings from the 2020 Autism Ontario Education Survey (pp. 1–20). Toronto, ON: Autism Ontario. Retrieved from https://www.autismontario.com/EduSurvey2020*

Caregivers were asked questions about themselves, their partner, and specific children under their care. If respondents had multiple children on the spectrum, they had the option to complete all child-specific questions for up to three children. Numerous questions asked caregivers about the above topics in the context of the COVID-19 pandemic. The survey consisted of two parts, taking approximately 15-25 minutes each (if completing for one child). Incomplete or invalid surveys were excluded prior to analysis. Since not all respondents completed all questions, the number of responses is provided for most questions.

WHO PARTICIPATED?

- **2,685 Ontario caregivers** completed at least some questions about the child(ren) or youth with an autism diagnosis in their care.
- Respondents completed questions for a total of **2,933 children**—with 223 completing questions for a second child, and 25 completing questions for a third child. 12.7% of caregivers indicated that they have more than one child with an autism diagnosis.

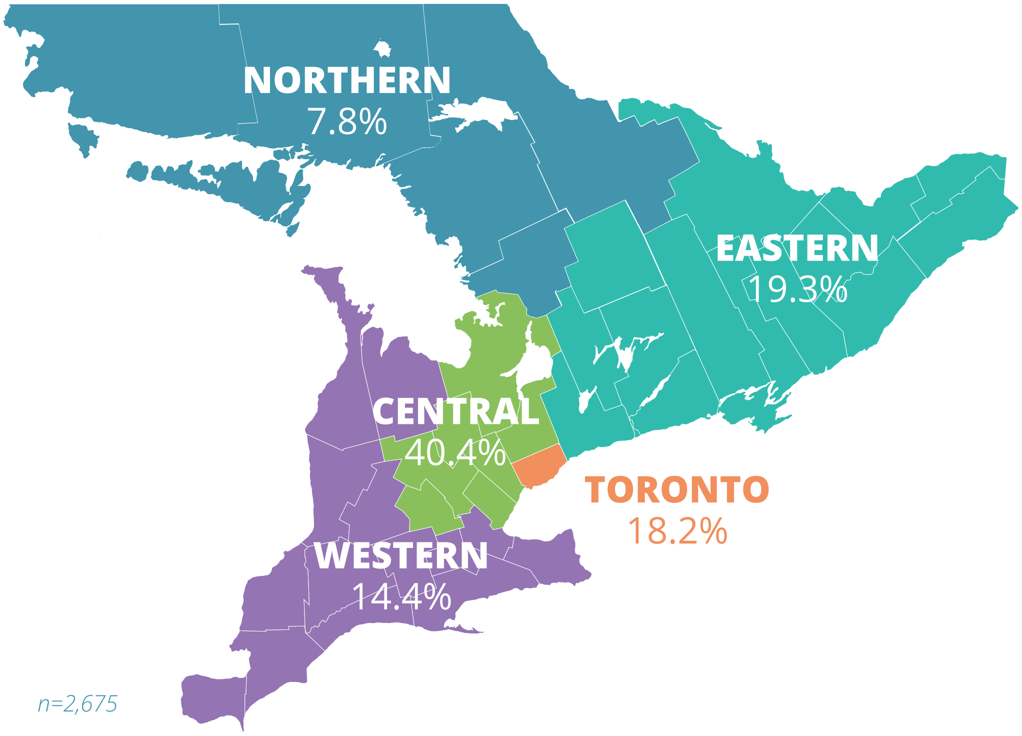
We estimate the responses to this survey provide information on **approximately 10% of the Ontario population of children 17 and under who are on the autism spectrum**. This is comparable to the reach of the previous Autism Ontario 2020 Education Survey *(n=2,413 caregivers).*

The demographic information below provides a partial picture of the types of parents and children whose information is captured here. It is important to acknowledge in the review of these results that some types of primary caregivers and their children may be under-represented in the data, while others may be over-represented.

RESPONDENTS' SPOUSAL RELATIONSHIPS AND SUPPORT *(n=2,590)*

Partner who provides support	44.8%
Partner but minimal support	30.0%
Single with minimal support	15.4%
Single with support from child's other parent or another family member	9.8%

RESPONDENTS BY REGION



PARTICIPANT CHARACTERISTICS

- **90.4%** of caregiver respondents are **female** *(<0.1% are non-binary) (n=2,666)*
- **11.0%** live in a wide-area **rural region** *(n=2,675)*
- **35.5%** live in medium or smaller population centres (population <100,000), where specialized services may be less available *(n=2,298)*
- **2.8% speak French most often at home** *(N=2,685).* This is below the population proportion of Francophone Ontarians (4.7%)[3]
- **13.7%** *(N=2,685)* most often **speak a language other than English or French** at home
- **38.1%** *(N=2,685)* are **not Canadian citizens by birth**
- **17.3%** of non–Canadian-born respondents *(n=1,010)* reported **residing in Canada for five years or less**
- **Average total household income in 2020** *(n=2,408)* was $86,604. (The Ontario average per 2016 Census was: $97,856)

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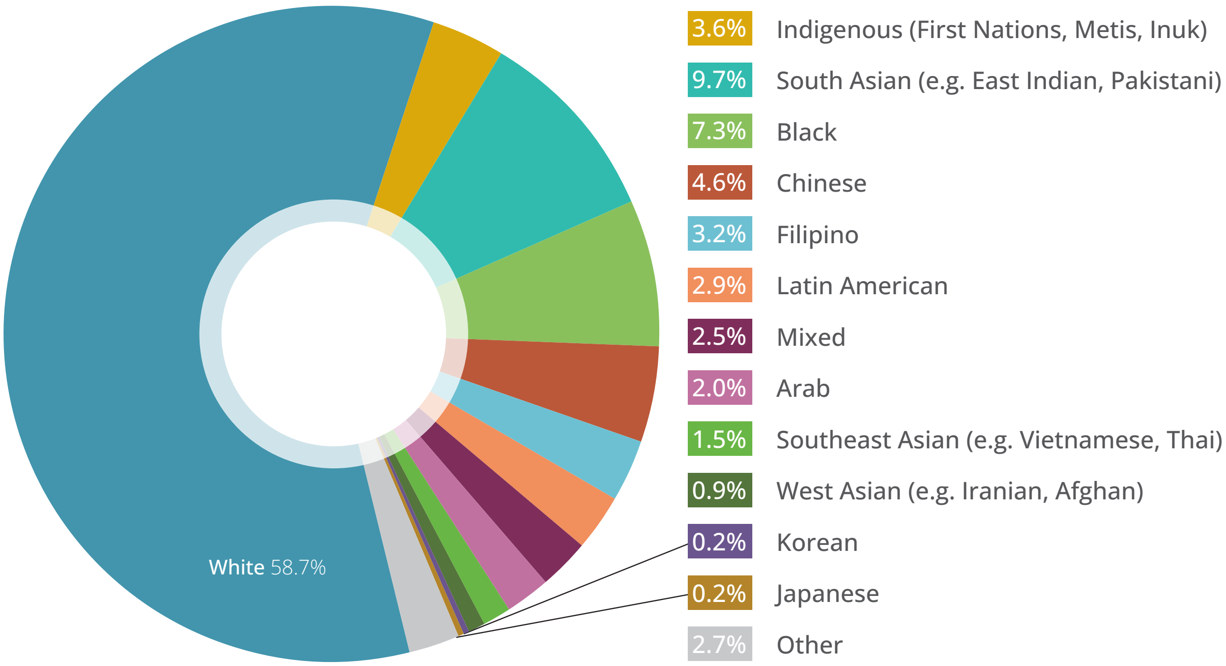
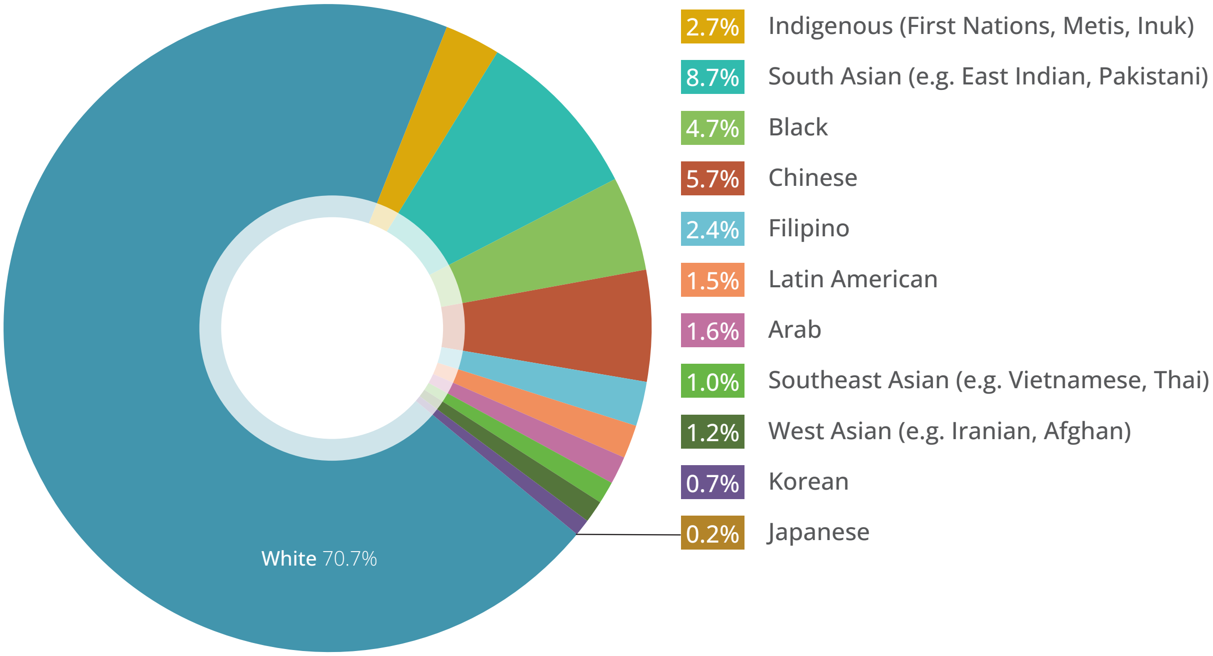
[3] *Reference: Profile of the Francophone population in Ontario – 2016, https://www.ontario.ca/page/profile-francophone-population-ontario-2016#:~:text=Ontario%20has%20more%20than%20622,000,increase%20of%2010,915%20since%202011*

INDIGENOUS AND RACIAL/ETHNIC IDENTIFICATION

RESPONDENTS *(n=2,588)*



FOR ALL ONTARIO*



**Per Census Profile, Ontario, 2016*

CAREGIVER EDUCATION LEVEL *(n=2,675)*

High School or Less	11.9%
Non-University Degree	43.0%
University Degree	45.2%

CHILD CHARACTERISTICS

Child ages ranged from 1 to 17 years, with a relatively uniform distribution for ages 3-17 (average 9.0 years) *(n=2,868).*

75.1% of children are male, 23% are female, and 1.9% are non-binary or gender questioning *(n=2,863).*

CAREGIVER-REPORTED CURRENT SUPPORT NEEDS OF CHILD *(n=2,820)*

Requires Support	48.8%
Requires Substantial Support	28.7%
Requires Very Substantial Support	22.5%

IN PERSON INSTRUCTION IS ESSENTIAL

1. CHILD EDUCATION

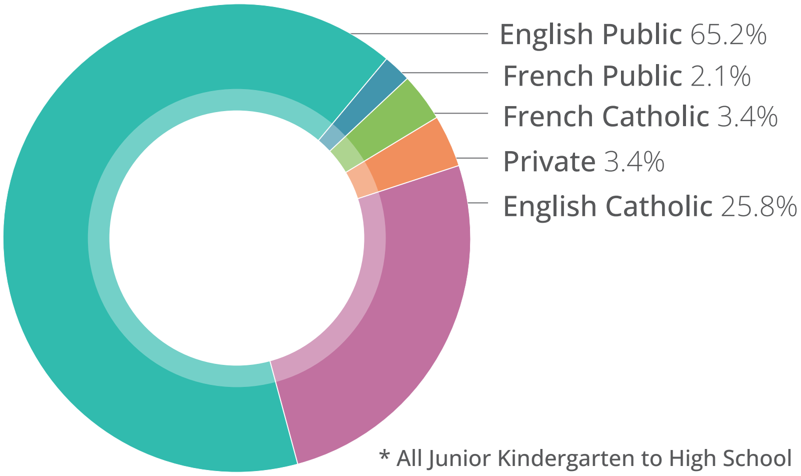
For the topic of child education, caregivers were asked questions about their child's placement in school and how the educational experience during the 2020-2021 school year was affected by the COVID-19 pandemic.

This included questions about the return to school in fall 2020 after the spring school shutdown at the end of the previous school year, the two province-wide school shutdowns that started in January and April 2021, online learning experiences, and aspects of the school year overall.

SCHOOL REGISTRATION STATUS *(n=2,774)*

- 10.2% *(n=283)* of children were not yet school-aged
- 3.3% *(n=92)* were school-aged but unregistered in any school for the 2020-2021 school year
  - The most common reason why these school-aged children were unregistered in 2020-2021 (cited by 97%) is that caregivers felt the education system could not offer the accommodations needed
- The majority of children attended English Public school, followed by English Catholic school

SCHOOL BOARD SETTING OF REGISTERED CHILDREN *(n=2,328)*

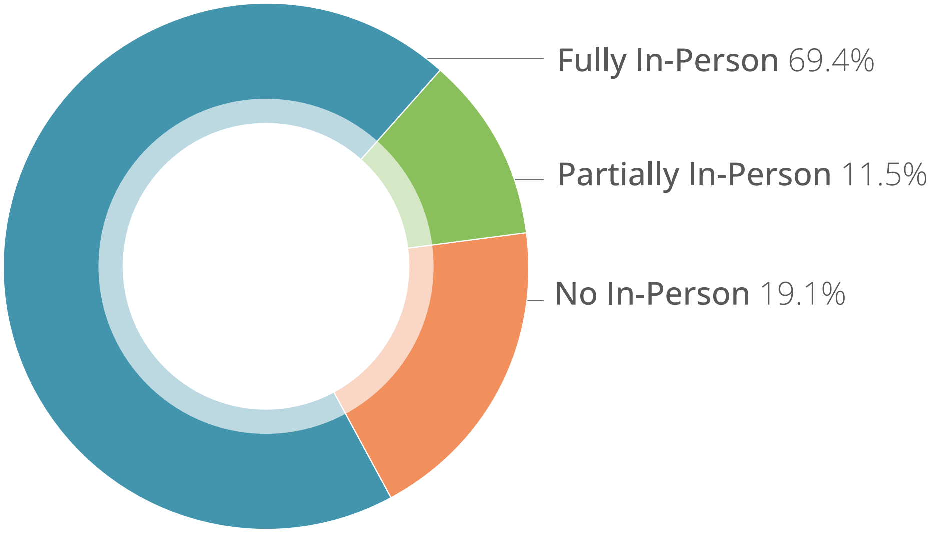


* All Junior Kindergarten to High School

FALL 2020 RETURN TO SCHOOL (NO PROVINCEWIDE SHUTDOWNS)

TRANSITION TO IN-PERSON ATTENDANCE IN FALL 2020 *(n=2,361)*

> While the majority of students returned in person in the fall of 2020, approximately one fifth did not



TOP REASONS WHY CHILD DID NOT START OR CONTINUE FULL-TIME IN-PERSON LEARNING

(n=567, multiple selections permitted)

Fear of child contracting COVID-19 (including risk of child passing it on to family)	64.1%
Child could not follow COVID-19 safety rules or expectations	40.2%
School could not offer accommodation needed	26.9%

EDUCATIONAL PROGRAMMING INSTEAD OF IN-PERSON LEARNING

(n=626, multiple selections permitted)

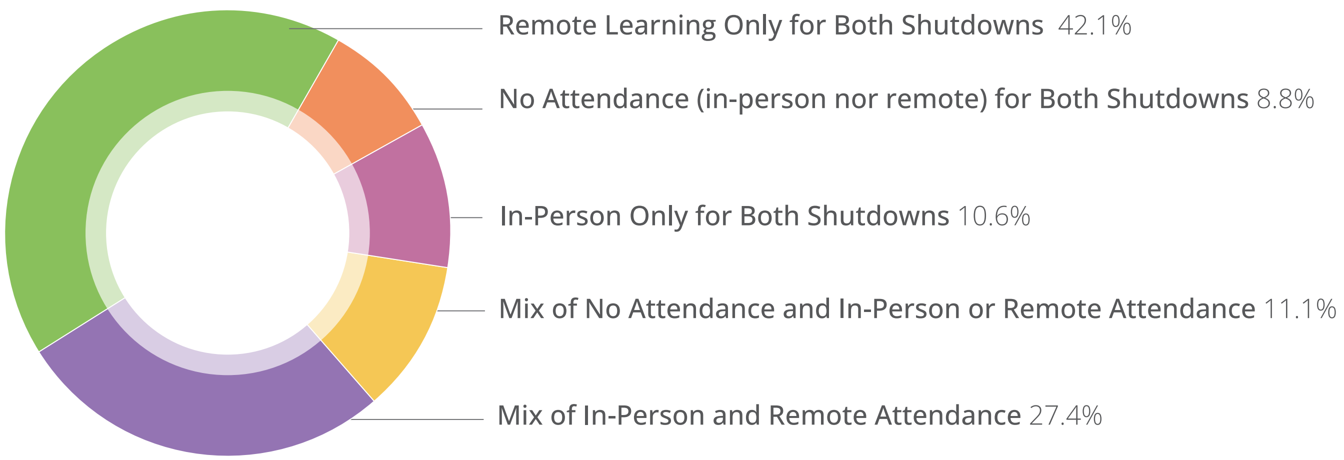
Remote learning registered with the child's school board	83%
Homeschool, private tutoring, or learning pod	9%
Therapy only	8%

2021 SCHOOL SHUTDOWNS

> *"From March 14, 2020, to May 15, 2021, Ontario schools have been closed for 20 weeks total, longer than any other Canadian province or territory."* [4]

HOW CHILDREN PARTICIPATED IN SCHOOL DURING THE JANUARY AND APRIL 2021 PROVINCE-WIDE SCHOOL SHUTDOWNS *(n=2,237)*

During the 2021 school shutdowns, the Ministry of Education allowed some students with high support needs to return to in-person learning. Despite this, only 10.6% participated in in-person schooling only for both shutdowns; around 20% did not participate in school (either remote or in person) at some point during the shutdowns.



REASONS GIVEN FOR NO IN-PERSON OR REMOTE LEARNING DURING SHUTDOWNS *(n=445, multiple selections permitted)*

Remote learning does not work for this child	68.5%
In-person learning was not offered during the province-wide shutdowns	39.6%
Education system could not offer accommodations needed	34.8%
No one at home was able to support this child's participation in remote learning	18.4%
Did not feel comfortable with the risk of COVID-19 infection with in-person learning	17.5%
Chose to provide child with homeschool option	10.3%
Chose to keep child in therapy	8.8%
Lacking technology (e.g., computer, iPad) or Internet access needed for child to participate in online learning	5.6%

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[4] *Reference: Gallagher-Mackay K, Srivastava P, Underwood K, et al. COVID-19 and Education Disruption in Ontario: Emerging Evidence on Impacts. Science Briefs of the Ontario COVID-19 Science Advisory Table.2021;2(34). https://doi.org/10.47326/ocsat.2021.02.34.1.0*

Among caregivers who described what would have been necessary for their child to remain in school *(n=327)*, about half highlighted in-person learning. This suggests that many children with an autism diagnosis who could have benefited from in-person supports were not provided this option.

> “In person would have been ideal. He needs that structure and routine that school provides. I felt that he fell through the cracks of the school system even more than usual during the shutdowns. During the first lockdown the school sent links and I printed them for my son to complete (child was not on computer at all). This worked out better than online for 6 hours.”

> “What I needed was for the school to provide in-person learning for my son. That would have been the solution. I had expected an exception would have been made for a 5-year-old with autism who doesn't have the attention span for remote learning.”

> “Autistic children have self-care goals like toileting and communication with a device, that can only really be taught in-person. I tried my best as a mom, but we needed that extra support.”

ENGAGEMENT IN ONLINE LEARNING

Based on caregivers’ reports, 8.5% of children **did not have sufficient access to the technology needed to support online learning** during the 2021 school shutdowns *(n=1,314)*. This is an apparent improvement from the 2020 Autism Ontario Education Survey, when 13.8% of caregivers reported their child lacked sufficient access to the technology to support online learning for the spring 2020 shutdown.

This reported lack of sufficient access to the technology to support online learning did not vary significantly between the five Ontario regions, although it appeared to be somewhat higher for Northern Ontario students (*see table below*).

PROPORTIONS OF CHILDREN WITH INSUFFICIENT ACCESS TO THE TECHNOLOGY TO SUPPORT ONLINE LEARNING BY ONTARIO REGION

Central Ontario *(n=552)*	7.2%
Eastern Ontario *(n=253)*	10.3%
Northern Ontario *(n=85)*	14.1%
Toronto Ontario *(n=247)*	9.3%
Western Ontario *(n=177)*	6.2%

Chi-square (df)= 6.971 (4), p=0.14.

With respect to remote education, 7% of caregivers reported their child **was not at all engaged in online learning**; 50% reported their child was **poorly engaged**; 29% reported their child was **moderately engaged**; and 14% reported their child was **well engaged** *(n=1,308)*.

Child engagement in online learning varied significantly with age (reflecting grade level). Engagement tended to be poorer for children ages nine years and younger (*see Appendix B, Table 1 for supporting analysis*). This finding is consistent with the 2020 Autism Ontario Education Survey, where engagement in online learning was reported to be poorer for children in Grade 3 and below.

"There is a big difference between engagement and learning. He loved chatting with friends, watching videos, listening to the music, however he didn't learn anything new and developed severe anxiety."

"Went on every day, but barely listened or understood."

"My child has significant learning disabilities in relation to reading, writing, comprehension, attention and focus. They were not able to keep up with the assignments, understand the assignments, delivery method was ineffective and far too fast-paced, not consistent and meeting the requirements or application as set out in his learning plan. His grades are reflective of a child who experienced many meltdowns due to frustration and inability to meet and keep pace with the requirements."

"Remote learning heightens child's documented challenges in turn taking, focusing, difficulties with lagging technology, not having physical cues to navigate social world more successfully.... Required 1:1 work with me in order to do anything for the day, resulted in constant battles over school when he needed parent to focus on his emotional needs not assume teacher role. Too stressful for kids with ASD to have parents wear 'multiple hats', when roles have to be clearly delineated and predictable."

"She would only be engaged if someone was there guiding her though it, and even then, it was a struggle. It often resulted in violent outbursts. Many items in my home were thrown and destroyed. I have bruises all over my body. This year has been a mess."

OVERALL SATISFACTION

- Caregivers reported their level of satisfaction with their child's educational experience during the COVID-19 school shutdowns in 2021 as dissatisfied or very dissatisfied (47.4%), neither satisfied nor dissatisfied (18.4%), or satisfied or very satisfied (34.2%) *(n=1,776).*
- Reported satisfaction with the 2021 shutdowns did not vary significantly by school board setting, level of child support needs, provincial region, or rural status.
- Satisfaction varied significantly with racial/ethnic identification. The level of satisfaction tended to be lower for racialized caregivers than for their white counterparts *(see Appendix B, Table 2 for supporting analysis).*
- Satisfaction also varied significantly with in-person vs. remote learning during province-wide school shutdowns. The level of satisfaction tended to be higher for in-person learning and lower for remote learning *(see Appendix B, Table 3 for supporting analysis).*

"His teacher was an all-star. She did everything she could, but it was a horrible situation and a terrible model. The Ministry mandated hours was over the top and ridiculous. By mid-May, we were only attending 2/4 classes a day; he couldn't handle ALL day in front of a screen, and I couldn't get any work done trying to supervise him."

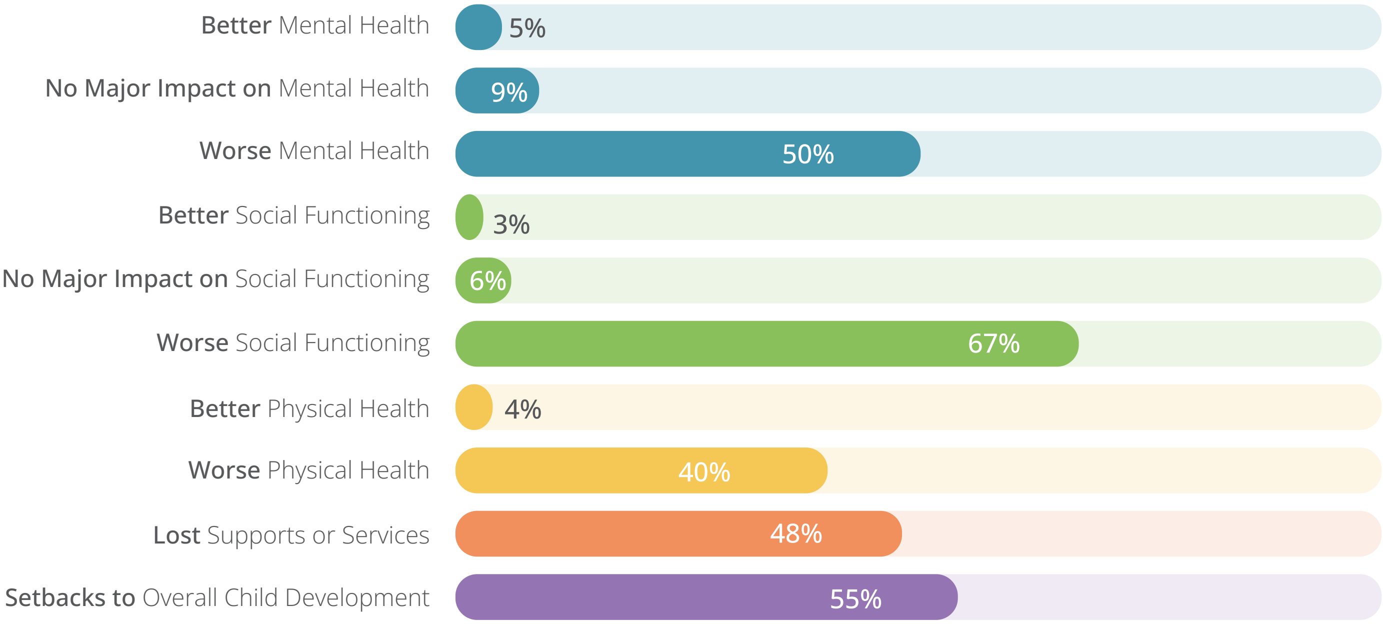
"When your child's human rights are being ignored and they are being discriminated (against) because of non provision of what accommodations are required year after year it gets extremely frustrating to say the least."

"When special education needs children were allowed to attend school in person, I was told by our principal that he was not allowed to because he was not in a county classroom, even though he will be placed in one in the next year or two. I felt he was not supported at ALL and that his education was not a priority or 'deserved'."

"We think he did fairly well because he had one-on-one support for his academic needs. It's unfortunate there are not EAs in every classroom to support students with ASD. Can you imagine what these children could accomplish with more support?"

"We had to advocate for all programming received. The burden was on us to make things happen and it was quite difficult overall."

CAREGIVERS' IMPRESSIONS OF THE IMPACTS OF THE APRIL 2021 PROVINCE-WIDE SCHOOL SHUTDOWN ON THEIR CHILD *(n=1,747; Respondents could optionally select multiple options as applied to their child)*



"My child was badly bullied in school. Participating in online school and activities remotely allows them more control over their own environment and contact with others."

"To quote my son doing online schooling... 'I've never been so lonely in my life'... This from an 11-year-old child."

"We feel we have lost so much. It feels like there has been unimaginable amounts of regression. This is all due to losing services, and not being able to participate remotely. Our child has no interest in anything virtual."

"They [school shutdowns] destroyed our life."

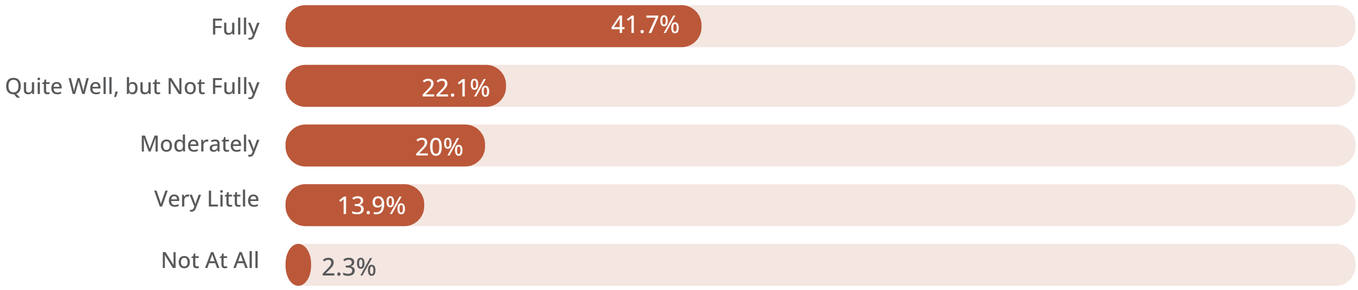
"The frequent lockdowns greatly disturbed the routine of the child, and he had a tough time settling to new routines."

THE FULL SCHOOL YEAR

OVERALL 26% OF CHILDREN MISSED 21 OR MORE WEEKS OF IN-PERSON SCHOOL ATTENDANCE FOR ANY REASON OVER THE 2020-2021 SCHOOL YEAR *(n=2,085)*

5 days or less	23%
1- 4 weeks	18%
5-20 weeks	32%
21+ weeks	26%

CAREGIVERS' SENSE OF THEIR LEVEL OF INVOLVEMENT IN THEIR CHILD'S EDUCATION OVER THE SCHOOL YEAR *(n=1,723)*



Greater involvement and awareness of their child's education was a noteworthy result of the shift to at-home learning identified by caregivers in the previous 2020 Autism Ontario Education Survey. The level of involvement was similarly high for a majority of caregivers over the 2020-2021 school year.

Among parents who expanded on their level of involvement in their child's education over the school year, many commented on how this involvement conflicted with work or other demands.

> "Constant advocacy in a system that doesn't have much to offer my child. Constant need to facilitate teaching at home in order to help child get through. One-to-one, 24 hrs/day. Prohibitive from maintaining any other duty or responsibility as a single parent."

> "While we have engaged fully and respectfully with our school and board it has not benefited our child in any way. If anything, it has hurt him. The public education system is set up like a dictatorship. If you do not agree with those in positions of power, your only recourse is to appeal through processes controlled by the same people you disagreed with. If you seek assistance from professionals outside the school system this only exacerbates the situation."

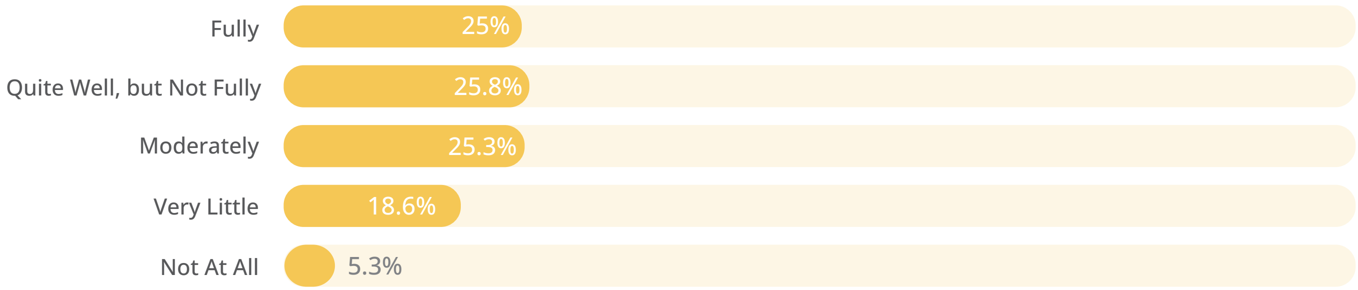
> “The school did not teach my child. They gave him an omission from synchronized learning because he could not sit in front of a computer all day, so everything he learned was from me.”

> “With aggressive physical behaviour towards myself and our respite worker, there was only so much we could do to support my child’s education at home without behaviour interventions.”

> “Was working full-time and found the educational support needs of both sons (one with ASD and the other with ADHD) overwhelming, so had to leave my job.”

EXTENT TO WHICH CAREGIVERS FELT THEIR CHILD’S EDUCATORS ACKNOWLEDGED THEIR CONCERNS OR REQUESTS SINCE START OF THE SCHOOL YEAR *(n=1,669)*

Many caregivers recognized teachers’ efforts, with 51% indicating **their child’s educators acknowledged their concerns or requests “quite well” or “fully**.” However, this leaves a similar proportion (49%) who felt their concerns or requests were acknowledged “moderately,” “very little,” or “not at all.”



> *“L’enseignante ressource de mon fils a essayé de son mieux de nous soutenir et trouver des solutions. La direction a été de peu d’aide et le conseil scolaire n’a été d’aucune aide et m’a laissé avec l’impression qu’il manque beaucoup de compréhension sur l’autisme. Je trouve que c’était de la discrimination à cause de son autisme.”*
>
> *[TRANSLATION] “My son’s resource teacher did her best to support us and find solutions. The principal was of little help and the school board was of no help at all and left me with the impression that there is a big lack of understanding about autism. I think that this was discrimination because of his autism.”*

> “We had a great online teacher who understood his needs and did her best to accommodate him and try to get him to participate, e.g., passion project using Minecraft.”

"School did their best, but were clearly overwhelmed."

"Because the learning was remote, it was a laissez-faire approach. The onus fell on parents to teach, supervise, review, regulate..."

"It took A LOT of advocating and fighting for my child's right to be back in school. The Government of Ontario allow[ed] Special Education programs to proceed for a reason, as it is vital for these vulnerable children. My child's principal was not in agreement, so it did take a lot of advocating for our concerns to be heard and acknowledged."

With respect to school exclusions, 23% of caregivers reported occurrences of their **child being sent home over the school year** because the school did not have the proper supports to manage issues related to a child's behaviour or due to safety concerns (i.e., school exclusions) *(n=1,725)*.

This appears to be an improvement from the 2019 LARC Survey Report, which found that 27% of children had been sent home in the previous 12 months. Note, however, that school exclusions would not be applicable to the proportion of children attending school remotely during COVID-19, and that these students could include a higher proportion of those who could not be adequately accommodated by their school in the first place (i.e., more likely to be sent home if they had attended in person).

AMONG PARENTS WHO CHOSE TO EXPAND ON EXPERIENCES OF THEIR CHILD BEING SENT HOME FROM SCHOOL OVER THE SCHOOL YEAR (I.E., SCHOOL EXCLUSIONS, CAREGIVERS MENTIONED THE FOLLOWING *(IN ORDER OF FREQUENCY, n=140)*

Exclusions were not applicable to the child this year because of remote learning

Exclusions due to lack of resources (e.g., educator staff)

Exclusions due to school's lack of ability to manage issues related to this child's behaviour

Successful prevention of exclusions due to interventions or accommodations provided

"When my child's EA called in sick and there would never be a supply EA, that meant I had to keep my child home."

"When schools have no resources or support staff to assist, all they can do is send students home."

"He was never sent home. We were told not to send him."

> “Our child was expected to do tasks that were challenging to any 4-year-old, such as putting his jacket on and zipping it up without assistance. He wasn't given a chance to improve. He was reduced from full day to half day, and even then, he got sent [home] almost every day after two hours. One time, they let him wait in the cold without his jacket on.”

CONCLUSIONS

Following the first COVID-19–related school shutdown from March-June 2020, approximately 70% of caregivers’ children with an autism diagnosis transitioned directly back to in-person schooling in fall 2020. While educational programming among the remaining 30% was predominantly remote learning offered by the child’s school (83%), some opted for therapy (8%), homeschool (7%), or other private learning arrangements (2%). Thus, many children received a significant amount of their education outside of schools.

Levels of satisfaction appeared to be lower for racialized caregivers when compared to white caregivers

Later in the school year, during the January and April 2021 province-wide school shutdowns, some children with special education needs were provided with in-person education. However, only 11% of children attended in-person school during both shutdowns. Meanwhile, 42% engaged in remote learning only, and 27% participated in a mix of in-person and remote learning.

A further 20% of children apparently “fell through the cracks,” participating in neither in-person nor remote learning at some point during the shutdowns—among these, caregivers reported that 40% of children were not offered in-person learning, and many caregivers commented that in-person learning would have been needed or helpful to keep their child in school.

Thus, it seems that if school boards had offered an in-person option to more students with an autism diagnosis, fewer children would have experienced periods of “no school at all” during the shutdowns.

Caregivers reported that 8% of children who participated in remote learning did not have sufficient access to the technology needed to support online learning during the 2021 school shutdowns. However, almost 60% of children were reported to be poorly engaged, or not engaged at all, in online learning, with children aged nine years or less more often than not falling into this category.

Almost 50% of caregivers reported being dissatisfied or very dissatisfied with their child’s education during the school shutdowns. Levels of satisfaction appeared to be lower for racialized caregivers when compared to white caregivers; a finding that is particularly concerning, given its implications for equity and non-discrimination.

Caregivers’ observations of the impacts of the April 2021 province-wide shutdown on their children were predominantly negative, including for mental health (50%), physical health (40%), social functioning (67%), and overall development (54%).

Despite this, caregivers reported some positive experiences with educators’ efforts during the shutdowns, with 76% reporting that their child’s educators acknowledged their concerns or requests over the school year. Instances of children being sent home due to schools not having the proper supports to manage issues related to child behaviour or safety were reported for 23% of schoolchildren over the school year—even though the proportion of children doing remote learning meant that fewer were able to be sent home during the COVID-19 pandemic in the first place.

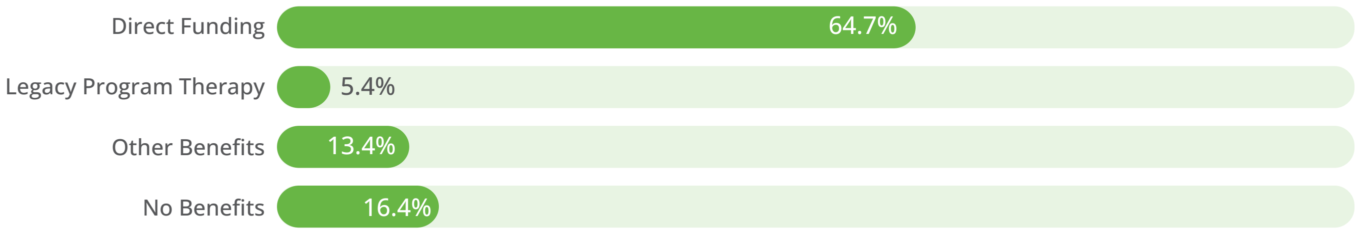
Together, these findings suggest that children with an autism diagnosis were particularly vulnerable to receiving unsatisfactory or inadequate education over the 2020-2021 school year.

II. AUTISM SERVICES, SUPPORTS & RECREATION

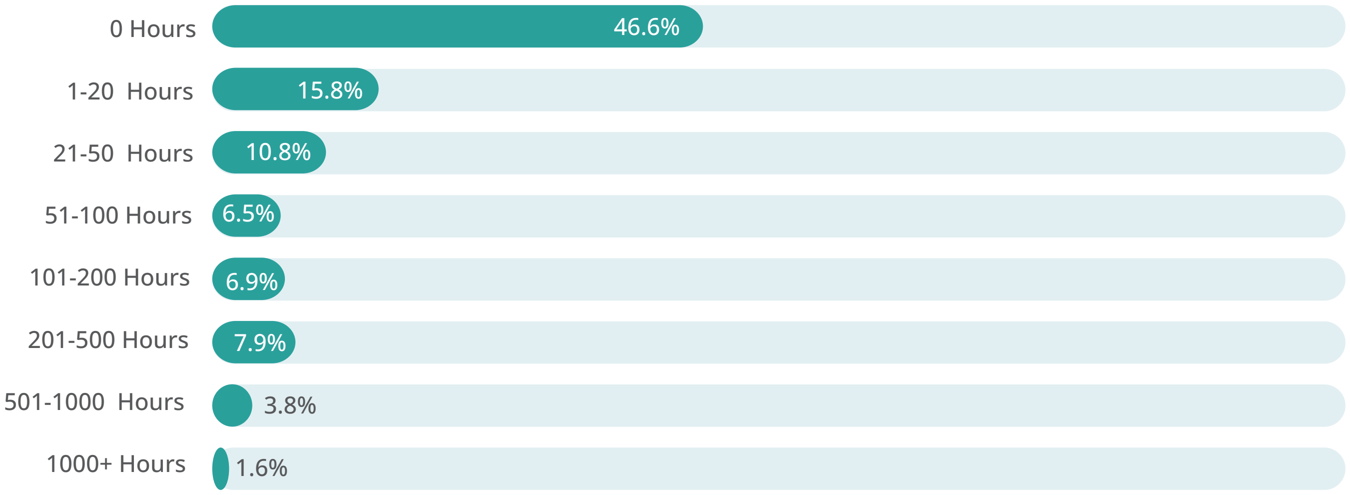
For the topics of autism services, supports and recreation, caregivers were asked questions about the Ontario Autism Program, service access in the context of the COVID-19 pandemic, and child recreation and physical activity.

ONTARIO AUTISM PROGRAM (OAP)

OAP BENEFITS RECEIVED FOR CHILD IN PAST 12 MONTHS *(n=2,698)*



APPROXIMATE HOURS OF OAP-FUNDED THERAPIST-DELIVERED SERVICES CHILD RECEIVED OVER PAST 12 MONTHS *(n=1,699)*



WHEN ASKED TO EXPAND ON THEIR EXPERIENCE OF HOURS OF OAP-FUNDED THERAPIST SERVICES OVER THE PAST 12 MONTHS, CAREGIVERS MENTIONED THE FOLLOWING *(IN ORDER OF FREQUENCY, n=384)*

COVID-19–related disruptions, barriers or changes to services

Wait-times or delays to accessing or receiving funding

Not receiving funding due to uncertainty or confusion (e.g., about eligibility)

Non-financial, non–COVID-19-related barriers to services such as travel, local availability, or timing

Insufficient funding preventing optimal therapy or service

> "It was very difficult to secure services needed as a parent who is new to this and doesn't know which services are needed. Further the service providers in this area are often booked out for a year to a year and a half, so getting services during a pandemic or even getting pointed in the right direction was difficult."

> "His window of 'early intervention' was lost waiting."

> "Funded hours only lasted 3 months, then funding ran out."

> "$5000 one-time funding is far from meeting the needs of my son. Didn't see much progress/impact from less than 100 OAP-funded hours. My son has severe autism and high needs."

CAREGIVERS' ESTIMATE OF THE EXTENT TO WHICH THE OAP HAS MET THEIR CHILD'S THERAPY AND SUPPORT NEEDS IN THE LAST 12 MONTHS *(n=2,234)*

WHEN ASKED TO EXPAND ON HOW MUCH THE OAP MET THEIR CHILD'S NEEDS IN THE LAST 12 MONTHS, CAREGIVERS MENTIONED THE FOLLOWING *(IN ORDER OF FREQUENCY, n=792)*

Needed supports or services that were not received, funded, or available

Insufficiency of OAP funds to meet needs

Service disruptions or restrictions due to COVID-19

Benefits of funding for the child

> "I have never gotten support on how to even navigate the support. So overwhelming. I said forget it and just survived."

> "I pay for services in Gatineau, Québec (SLP+OT, about 20.000$ a year) and this cannot be covered by OAP. With OAP, I can buy stupid cheap stuff made in China from Amazon though... but excellent, professional services 3 kms away from my place, no... because it is in Quebec. How could this be more stupid?"

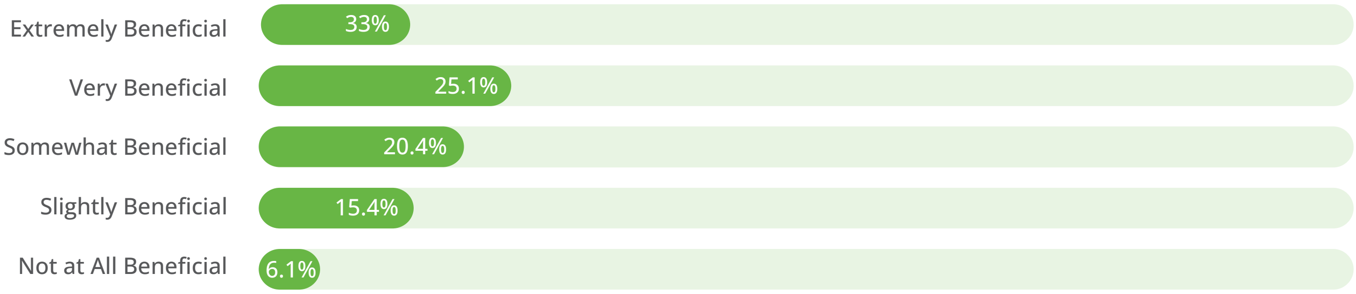
> "Without the OAP one-time funding I wouldn't be able to pay for all the ABA and OT done during the lockdown and it would impact even more his development and his mental health"

> "We've been on the wait list for speech therapy for a good 8 months I believe. Waitlists are about 1.5 years, which means using the one-time funding is not an option, since it will expire (even with the extension) before we get in."

> "With lockdowns, it was difficult to spend the money of OAP one-time funding directly on therapy services. Funding went a lot to items to use in the house. Although items purchased have helped, would have preferred to spend on actual therapy. Also waitlist to get into therapy after lockdown was difficult. Like government just threw money at the problem, instead of investing time and energy on getting (more) providers or education programs to get more providers."

CAREGIVER PERCEPTIONS OF HOW BENEFICIAL OAP FUNDING HAS BEEN FOR THEIR CHILD'S LIFE *(n=1,517)*

Despite the comments above regarding how much the OAP met their child's needs in the last 12 months, over 78% of caregivers reported that OAP funding was somewhat to extremely beneficial for their child's life.



WHEN ASKED TO EXPAND ON THEIR PERCEPTIONS OF HOW BENEFICIAL OAP FUNDING HAS BEEN FOR THEIR CHILD'S LIFE, CAREGIVERS MENTIONED THE FOLLOWING *(IN ORDER OF FREQUENCY, n=618)*

Funded therapies and services made a positive difference that could not be achieved otherwise

Funding was insufficient to cover the necessary expenses

Funded therapies and services helped the caregiver or family unit in addition to the child

COVID–19-related challenges or service disruptions

Desired services were not covered

Access barriers, challenges, or problems with receiving services (non-financial and non-COVID-19-related)

> "He wouldn't be able to communicate at all without that program. But he also can't develop further because we are out of funding."

> "My child is one of the few lucky enough to have funding. He has severe needs and has made huge gains. We would be in extreme crisis without therapy."

> "Having funding is great and extremely beneficial, but the amounts are not enough when your child has severe needs. They need to increase the funding amounts for all ages."

> “I was not able to fully spend the funding due to Covid-19 restriction and the lack of service in French.”

> “If we had a needs-based kind of funding, it would help a lot more. Above the $5000 we get, it’s cost [me] $25,000 out-of-pocket for assistance. We had to sell our house in order to maintain the assistance that he needs.”

> “My child needs help now. The more we wait, the more ineffective the support will be.”

> “It would be nice to be able to know what the funding model would look like after the one time interim funding so we can plan ahead.”

> “It has been really stressful and frustrating with all the changes and delays made to OAP.”

PROPORTION OF CAREGIVERS WHO THINK IT IS IMPORTANT OR ABSOLUTELY IMPORTANT FOR PROVINCIALLY FUNDED AUTISM SERVICES TO FEATURE THE FOLLOWING *(n=1,907)*

WHEN ASKED TO EXPAND ON THEIR THOUGHTS ON THE IMPORTANCE THAT DIFFERENT FEATURES BE INCLUDED IN PROVINCIALLY FUNDED AUTISM SERVICES, CAREGIVERS MENTIONED THE FOLLOWING *(IN ORDER OF FREQUENCY, n=262)*

Reducing waitlists, and consequences of not doing so in terms of caregiver stress, delays reducing effectiveness of early intervention, costs of paying privately for therapy while waiting

Greater choice in services

Needs-based services or more funds

Data sharing and service coordination across providers including schools

Caregiver supports including for mental health and career challenges

Having had no access to services so far

Service navigation support

"It's important to have services provided in my city/in Northern Ontario. I have no interest in virtual services from Southern Ontario. Our needs are different in the North. We need services here live and in person and virtual services from the North."

"We just need any help at all. Waiting 6 + years is unbelievable"

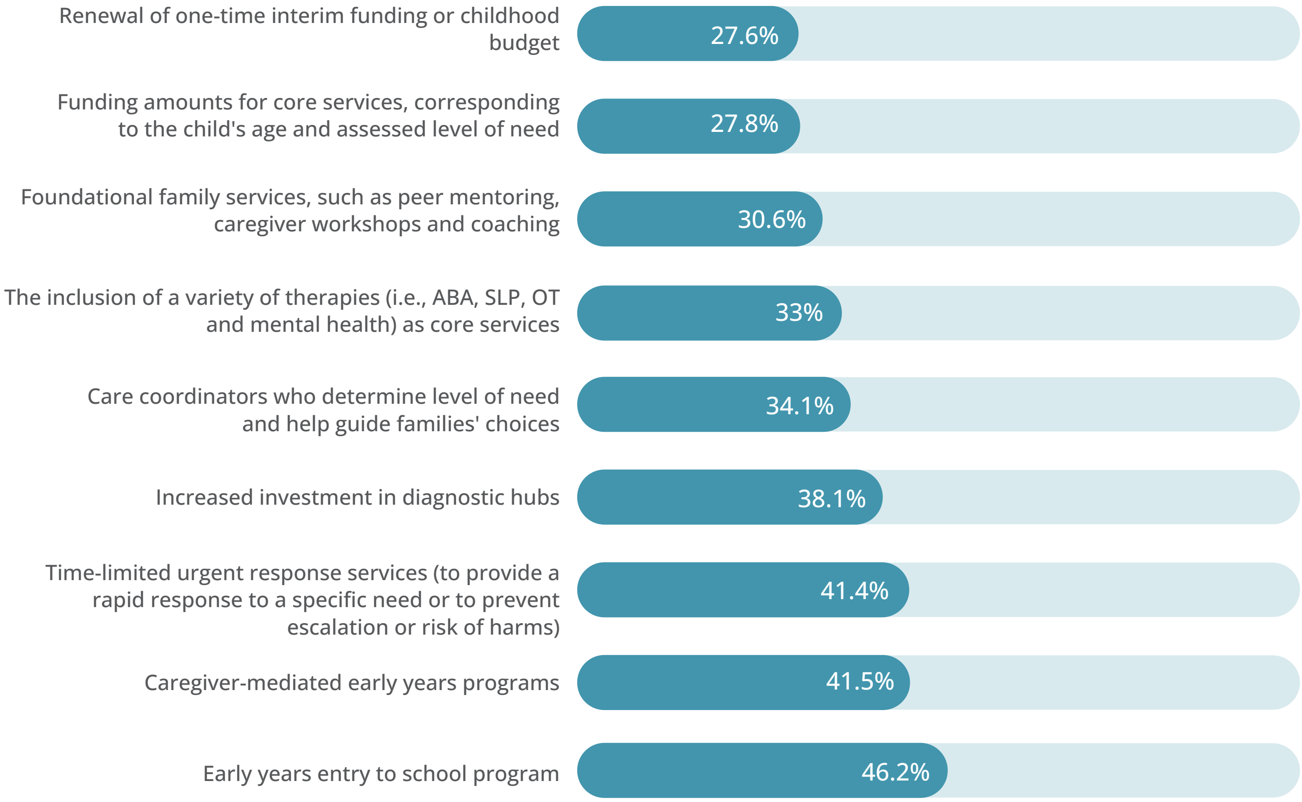
"We have struggled to coordinate support across a number of disconnected care professionals in the journey to understanding what our child was struggling with, we felt very alone and isolated and weighed down by the burden of trying to bring all the pieces together to get him and our family the help that was needed."

"We have waited for 10 months for mental health help for my 9 year old with ASD because of waitlists and no one knowing how to address ASD AND mental health, so we keep getting passed to another staff who has a wait. We signed up for intensive home intervention but are on waitlist and it's virtual."

"We were on a waitlist for 3 years, the most formative years where something should have been done...we knew (he) needed help but didn't know what kind of help from the age of 12 months, he was 2yrs and 4months before we got a diagnosis. This boy's whole life has been waitlisted by a flawed system."

As of July (when this survey was conducted), 50.4% of caregivers reported having heard about recent changes to OAP announced February 2021, while 49.6% had not heard about it *(n=1,874)*.

PROPORTIONS OF CAREGIVERS WHO REPORTED FEELING “SOMEWHAT” OR “VERY CONFIDENT” THAT LISTED COMPONENTS OF THE NEW OAP WOULD MEET THEIR CHILD(REN)’S AND FAMILY’S NEEDS *(n=1,862)*



Note: *There were two ways for parents to interpret this question affecting its reliability: (a) as a rating of desirability of each component, or (b) confidence that the responsible Ministry would succeed in incorporating the component to effectively meet their child(ren)’s needs.*

WHEN ASKED TO EXPAND ON THEIR CONFIDENCE THAT DIFFERENT INGREDIENTS OF THE NEW OAP WILL MEET THEIR CHILD’S NEEDS, CAREGIVERS MENTIONED THE FOLLOWING, *(IN ORDER OF FREQUENCY, n=299)*

Frustration with lack of services, insufficient funds, long wait-times, or uncertainty due to frequent program changes

Lack of hope or confidence in the government or OAP

Lack of understanding or knowledge about new OAP

Desire for different or better services

Concerns over aspects of the new OAP, such as the role of care coordinators

"We are left in the dark with regards to the new OAP. We have no idea when we will transfer into it and how much money we'll be getting. It makes it impossible to plan ahead, which is adding stress."

"With my experience of 6 years in Canada, I am not at all confident for any improvement. We lost all the hopes. So, whenever possible for us, we travel to our back home country from where we moved to Canada with a dream of better healthcare and education for my kids. Services in back home country are more affordable and easily available, no long waitlist, not $160 per hour of therapy."

"There should not be a cap on the amount of funding for a 'needs based' program. Care coordinators are bureaucrats and not clinicians. Needs and funding allocation should be determined by clinicians in the field and not by checking off boxes on a form particularly due to the complex and individualized nature of autism."

"The hardest part for me is the paperwork involved, I always have to focus solely on his deficits, basically writing over and over how 'wrong' he is or how 'terrible' being his parent is in order to qualify for funding to help him build his strengths. Mentally and emotionally it's heartbreaking and exhausting. I wish the funding was based on goals and plans instead of what he's 'lacking'."

"I cannot get a hold of anyone from the program in a timely manner. I work very stressful job full time and have 3 kids. I have spent hours and hours sometimes to find out about services and funding I can get for my son..."

"Time is passing and we cannot turn the clock back. I see my kids growing and missing all the learning opportunities they should be provided with to help them develop. The program must be implemented at once!"

"It is difficult for me to know if these changes will help.... Sadly, I have learned more about current funding programs through this survey than I have through the OAP or government. I have zero trust in the OAP program because of how little we've ever received in the past 10 yrs. I hope things get better. But they haven't yet, so we can't see beyond the current crisis."

“Our family lives in constant fear of the provincial government ripping our child’s funding away for services he desperately needs.”

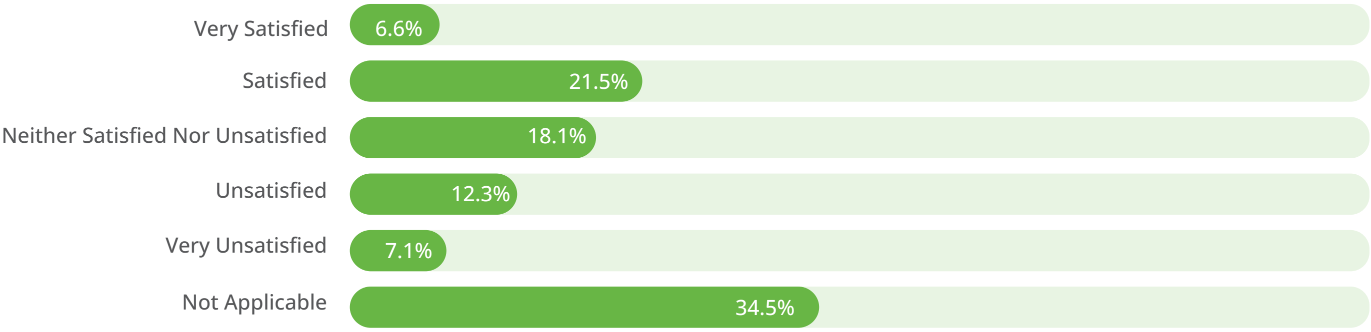
“I live in a rural community up north 2 hours away from the nearest biggest centre (which is not my district) and all that is offered is virtual therapies that don't work for my son. Most of the other therapies that we get are still waitlisted forever and the workers still need to travel that distance to get to us. It is overwhelming!!!”

AUTISM SERVICE ACCESS DURING COVID-19 AND BEYOND

In this section on service access during the COVID-19 pandemic, caregivers gave their perspectives about remotely delivered telehealth services, which became more predominant as a result of COVID measures.

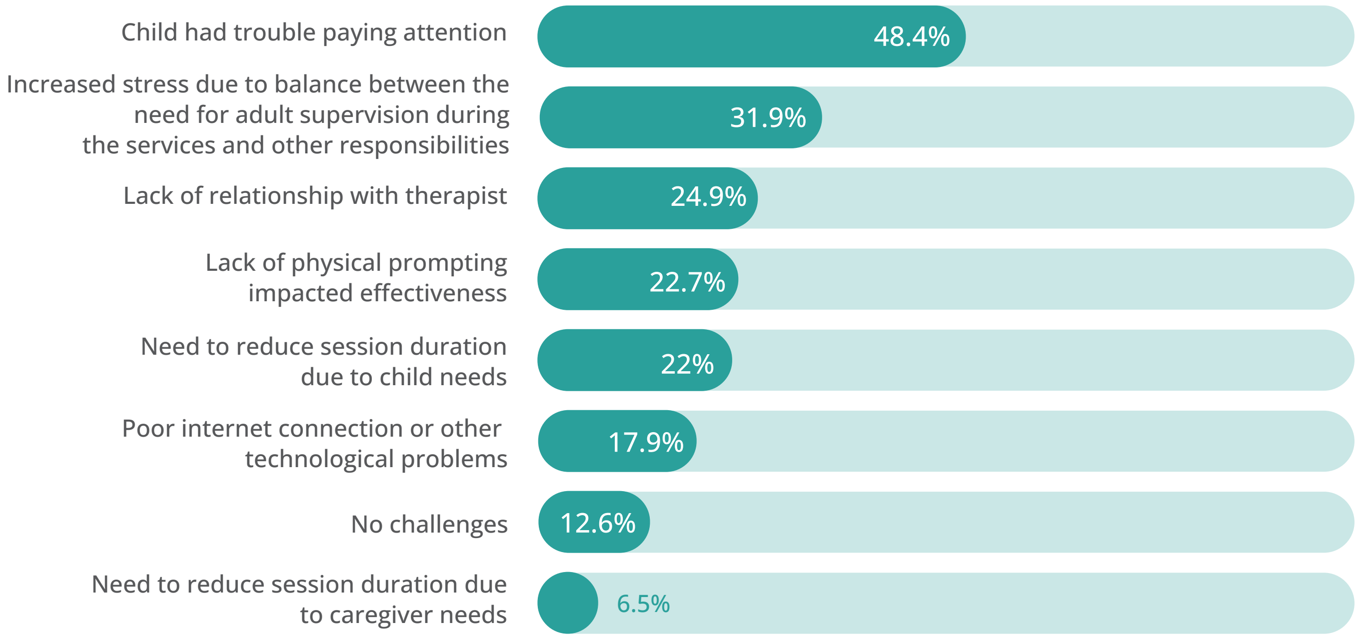
CAREGIVERS’ GENERAL LEVEL OF SATISFACTION WITH TELEHEALTH SERVICES FOR THEIR CHILD(REN) WITH AN AUTISM DIAGNOSIS *(n=1,772)*

Over 34% of caregivers indicated “not applicable,” presumably because their child(ren) did not participate in telehealth services. However, of those who participated, 42.9% indicated being satisfied or very satisfied with these services, 29.6% reported that they were unsatisfied or very unsatisfied, while the remaining 27.5% were neutral.



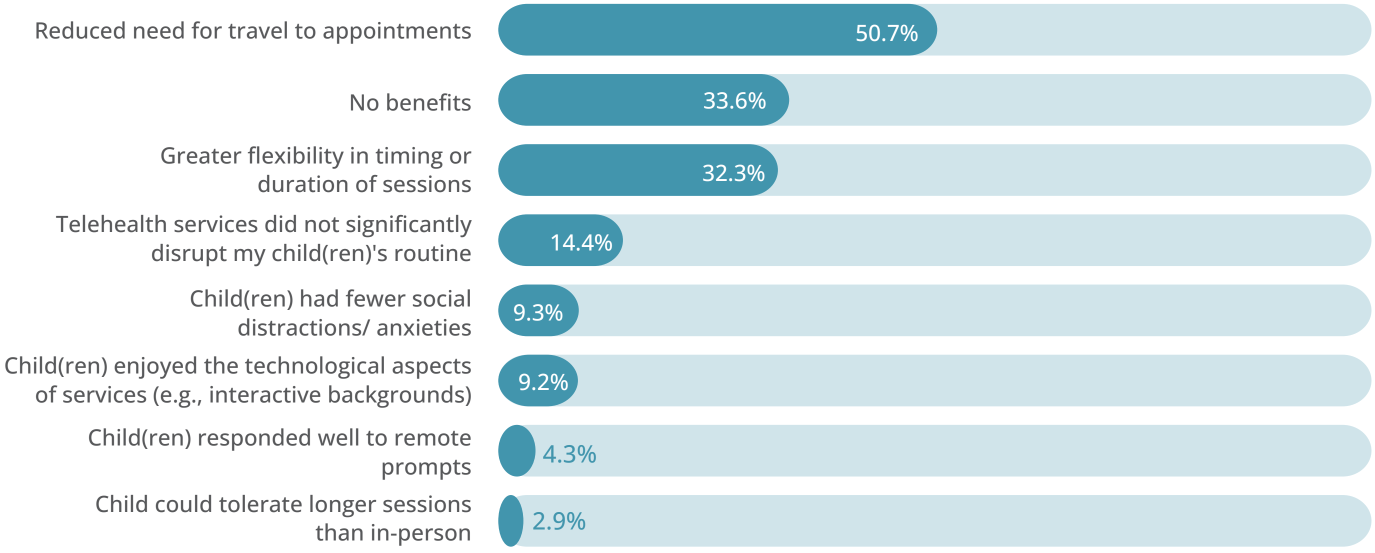
CHALLENGES WITH TELEHEALTH SERVICES EXPERIENCED BY CAREGIVERS *(n=1,929)*

Caregivers noted several challenges with respect to remote services, with the most common being that the child had trouble paying attention.



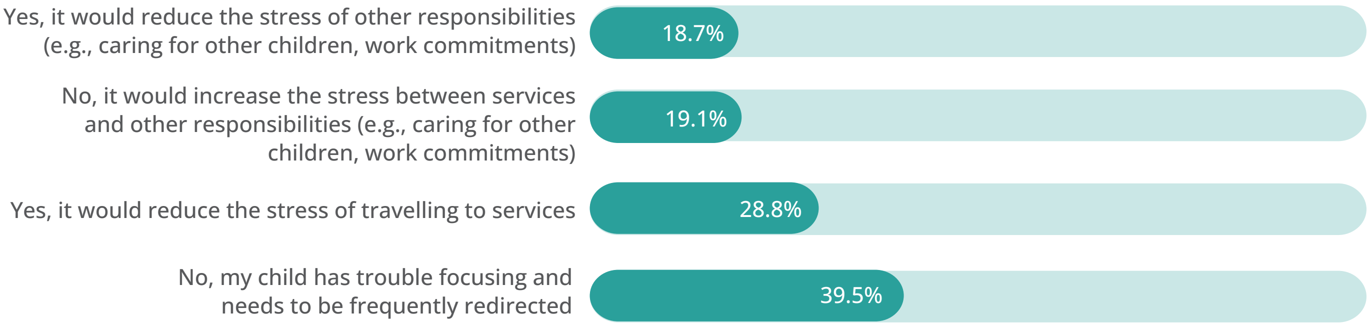
BENEFITS OF TELEHEALTH SERVICES EXPERIENCED BY CAREGIVERS *(n=1,606)*

Many caregivers also reported some benefits to receiving remote services. For example, half of caregivers described reduced travel as a benefit, while one third of caregivers reported no benefits at all.



Considering both the benefits and drawbacks of remote services, caregivers were divided on whether they would like to continue accessing them in the future.

IF THEY CONTINUED TO BE AVAILABLE, DO YOU BELIEVE TELEHEALTH SERVICES COULD IMPROVE YOUR FAMILY'S ABILITY TO ACCESS AUTISM SERVICES IN FUTURE? *(n=1,732)*

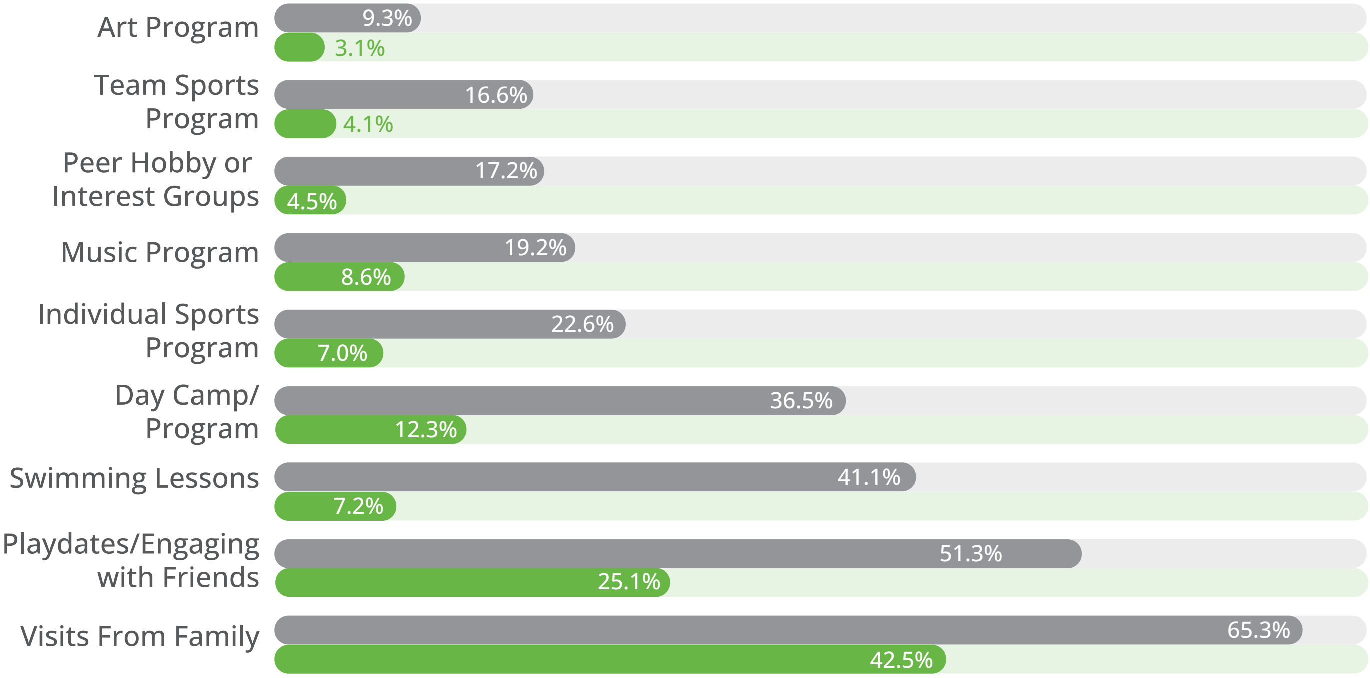


CAREGIVERS' PREFERENCE TO CONTINUE USING TELEHEALTH OR IN-PERSON SERVICES FOLLOWING THE COVID-19 PANDEMIC *(n=1,818)*

In-person only	51.7%
Mix of both telehealth and in-person	46.4%
Telehealth only	1.9%

CHILD RECREATION

REDUCTION IN PROPORTION OF CHILDREN PARTICIPATING IN RECREATIONAL PROGRAMMING OR ACTIVITIES COMPARING 2019 PRIOR TO COVID-19 *(GRAY BARS)* TO IN-PERSON DURING 2020 (*GREEN BARS)* *(n=2,019)*



In addition to participating in lower proportions in-person in 2020, small proportions of caregivers indicated their child(ren) participated in these activities remotely in 2020, presumably to make up for reduced in-person availability. This remote participation was slightly higher than in-person participation in 2020 for three activities: art, peer hobby or interest groups, and music. When asked to comment further on recreational programming or activities for their child during or before the COVID-19 pandemic, many caregivers mentioned disruptions or lost availability due to COVID-19.

> "He's become depressed and frustrated easier, always asks to go swimming or skating. Keeps saying he's a 'bad boy' cuz he isn't able to go out, even after being told they are closed."

> "Major loss for us. [He participated in] private swimming classes and martial arts pre Covid. Physical activity is our biggest challenge and we have lost momentum. Our son has sensory challenges so finding regular physical activities that he will do and find stimulating is challenging."

> "My daughter is on a track team and this is hugely important for her social skill development, sense of well-being and ability to self-regulate. She loves running and going to track practice is often the only group activity she enjoys and sometimes the only one she tolerates, as school is often too overwhelming for her. Running gives her a mood-boost and an energy infusion. There were times when Covid 19-restrictions meant her track team couldn't train at all, not even in distanced groups of less than 5. While I understand the need for lockdowns, restrictions did create an unusual challenge for us as the loss of the routine and outlet of track practice often meant my daughter couldn't do anything, including getting out of bed. For her, her track team is an essential support."

> "COVID killed all opportunities for in-person recreation and social skill development opportunities. She had made many gains in grade 1 and the first half of grade 2 before COVID hit, all of which have been lost."

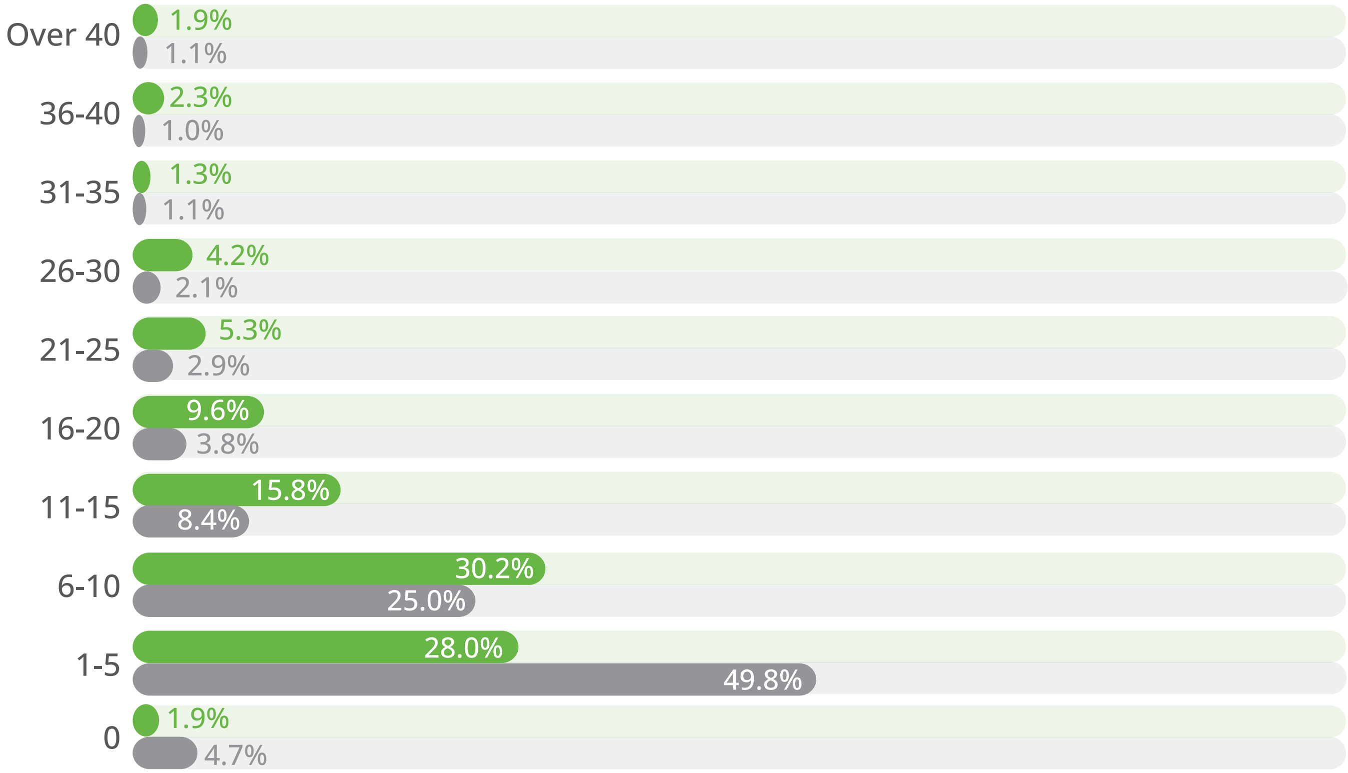
> "My child has had no outlet for her energy or to express herself. She is so sick of spending time with her mother. Covid 19 has massively strained our relationship. I have become her only friend. She has regressed in her social skills, as she only leaves the house for school. She has very little time to interact with peers."

> "My son has completely isolated himself and has not interacted with any of his peers since February 2020."

PHYSICAL ACTIVITY

CAREGIVERS' REPORTS OF CHILD HOURS OF PHYSICAL ACTIVITY IN THE PAST WEEK DURING COVID-19 (*n=1,966; GRAY BARS)*, AND DURING A TYPICAL WEEK PRE–COVID-19 *(n=1,934; GREEN BARS)*

Children participated in less exercise on average in a week during COVID-19 when 45.5% of children were estimated to participate in six or more hours of exercise in a week, compared to pre–COVID-19 when 70.1% of children were estimated to participate in six or more hours of physical activity in a typical week.



CONCLUSIONS

When asked about the type of Ontario Autism Program (OAP) benefits received in the previous 12 months, 16% of caregivers reported receiving no OAP benefits.

Meanwhile, many caregivers (53%) reported that the OAP met their child's therapy and support needs to a low extent or not at all in that time. Among caregivers who commented on this, many mentioned that their child needed additional supports or services that were not funded.

Caregivers described frustrations with long waitlists and insufficient funding in the childhood budget or one-time funding model, which provided set rates of $5,000 for children six and older, and $20,000 for those five and under. Thus, most caregivers felt that the current OAP was insufficient to meet their child's needs, with qualitative responses suggesting this to be particularly true for those with higher support needs.

Nevertheless, the OAP was rated as beneficial to their child's life by 78% of caregivers. Among caregivers who commented, many mentioned that funded therapies and services made a positive difference that could not have been achieved otherwise.

Others remarked, however, that the funding received was insufficient to cover the necessary expenses, and that while they appreciated the funding received, their child's goals could not be fully realized within its limitations.

When asked to indicate desired features in provincially funded autism services, caregivers most commonly endorsed a needs-based approach, followed by minimal wait-times, a strengths-based approach, family-centred care, integrated care, caregiver support, and remote service provision. Many expressed a sense of hopelessness, frustration with, and confusion over frequent program changes, or a lack of confidence in the OAP to provide adequate services for their children. It is important to note that at the time of the survey, the OAP was in a state of transition, and many of the new elements of the program, including crisis services and core funding, had been announced but not yet rolled out.

Many described significant losses in social skills and questioned whether these skills will ever be recovered.

There were substantial losses to children's recreational programming and unstructured social activities when comparing pre–COVID-19 rates of participation. Similarly, the proportion of children getting six or more hours of physical activity (including light, moderate or vigorous) per week during the pandemic (45%) was lower, when compared to before COVID-19 (70%). The losses to in-person recreational opportunities were likely important factors in parents' observations of deteriorations in the mental, social, and physical well-being of their children. They reported having fewer outlets for their child's energy, and of children that had become isolated and despondent, due to a lack of social interaction with their extended family, friends, and peers during lockdowns. As a result, many described significant losses in social skills and questioned whether these skills will ever be recovered.

III. CAREGIVER WELL-BEING

The caregiver well-being topic included questions about mental health, physical health, and caregiver self-care and support. These topics were asked about both in the context of COVID-19 and related to the challenges of accessing and navigating autism-related care.

CAREGIVER MENTAL HEALTH

CURRENT LEVEL OF STRESS* *(n=2,678)*

Marked	8.4%
Moderate	56.0%
Mild	35.6%

** Using the Brief Family Distress Scale: "On a scale of 1 to 10, please indicate where you and your family currently are right now, in terms of crisis." Mild: 1-3, Moderate: 5-6; Marked: 7-10. Reference: 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*

CAREGIVERS WILLING TO EXPAND ON THEIR LEVEL OF STRESS MENTIONED THE FOLLOWING *(IN ORDER OF FREQUENCY, n=381)*

Multiple demands such as childcare, work
Demands related to availability, navigation or accessibility of autism services
Autism-related concerns affecting the child
COVID-19-related challenges
Economic stresses such as personal finances, employment, difficulty affording services
Physical or mental health challenges
Resilience or coping strategies
Need for respite, social support, or time to themselves
Urgent care services or mental health crises

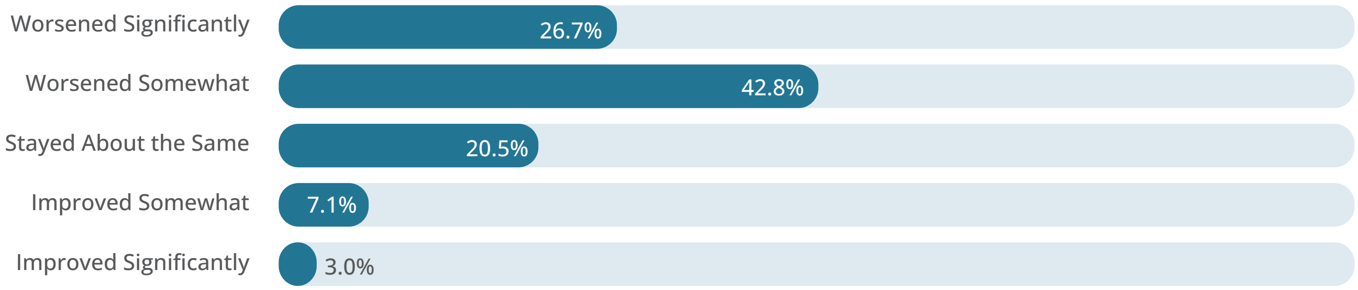
"I have been through all of those stages. It is always a continuous roller coaster of highs and lows. I am not complaining as it is what it is and the days that are good, make me feel proud and that we are moving forward and accomplish[ing] major milestones. When we are struggling or have struggled, it isn't fun to reach out and someone tell you there is no help and that the waitlist is 6 months to a year, as that makes the situation harder. I have dealt with anxiety and days of crying and struggling and begging, with no one and no answers."

"On se sentent vraiment seul sans support."
[TRANSLATION] "We feel really alone without support."

"Time is passing... I see my kids growing and missing all the learning opportunities they should be provided with to help them develop. I see forever waitlists. It is heartbreaking and so frustrating. I cry every day..."

"I don't know what to do. I don't know who to talk to. There is no help from my son's school. I am lost."

HOW CAREGIVER MENTAL HEALTH CHANGED DURING THE COVID-19 PANDEMIC *(n=2,561)*



THOSE WILLING TO EXPAND ON THE EFFECTS OF COVID-19 ON THEIR MENTAL HEALTH MENTIONED THE FOLLOWING *(IN ORDER OF FREQUENCY, n=533)*

Challenges related to work or working from home	38%
That mental health was worse earlier in the pandemic and later improved	29%
Worries about the child, increasing caregiver stress	26%

"My son has been significantly impacted by all the restrictions due to the pandemic, which in turn directly impacts the quality of life of all family members in our household."

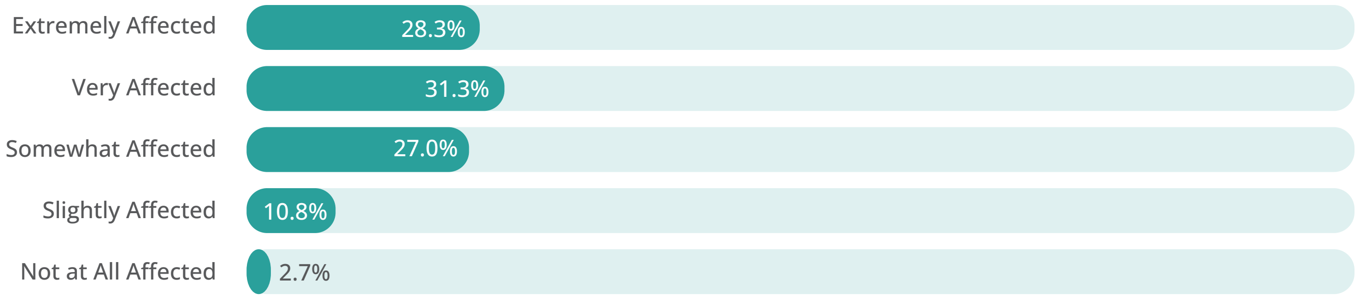
"Working full time from home and trying to help two kids with online learning was stressful and made for extremely long days. Hard to find time for self-care. Now that it is summer holidays my schedule has eased up. I am currently going to counselling once a month to help find coping strategies and I am also taking an ADHD/ASD parenting course."

"It's been a long time, with little respite, with little to do, disturbed routines and 3 children as a single mother. It's just been a longer year."

"I could no longer keep my long-term job of 13 years ...as I needed to stay home and care for my high needs child. We were left to ourselves as the world shut down and had no outside support or help for the majority of 2020. My child is physically aggressive, violent, verbally assaulting and has caused damage to my home and hurt me many times. There is no way to describe the trauma associated with living with a unregulated child..."

"Constantly juggling demands for multiple children doing remote and trying to work remote. Absolutely exhausting."

EXTENT TO WHICH CAREGIVERS FELT THAT THEIR MENTAL HEALTH HAD BEEN AFFECTED BY THE CHALLENGES OF ACCESSING AND NAVIGATING AUTISM-RELATED CARE *(n=1,808)*



This can be compared indirectly to the *2019 LARC Survey Report*, where respondents were asked a slightly different question—about the extent to which their mental health was affected by "managing the stressors of autism in their family." Responses in that survey were as follows: 29% extremely affected, 42% very affected, 21% somewhat affected, 7.5% slightly affected, and 0.5% not at all affected.

Note: No statistical comparison was made because these two sets of results are from different sets of respondents whose demographics were not the same, and the questions asked were different.

Caregivers reported spending an average of 5.9 hours per week advocating *(n=1,495)*, and 9.3 hours per week navigating care *(n=1,577)* for their child(ren) with an autism diagnosis. This is less than was found in the *2019 LARC Survey Report*, where respondents reported spending an average of 10 hours advocating and 14 hours navigating care. Different respondent demographics, and different time pressures brought about by the pandemic, among other reasons, may underlie these differences.

WHEN ASKED TO COMMENT FURTHER ABOUT PROVIDING ADVOCACY AND SUPPORT FOR THEIR CHILD(REN) WITH AN AUTISM DIAGNOSIS, CAREGIVERS MENTIONED THE FOLLOWING *(IN ORDER OF FREQUENCY, n=265)*

It is a considerable amount of work that burdens parents and contributes to stress

More services, supports or programs are needed

The need for advocacy can vary by circumstances or time periods

> “Ever since...the day we were told our son had Autism...I have felt pressure. Pressure that I should spend time most days after my children have gone to bed reading about Autism, looking at ways to support my son, listening to podcasts, taking courses to better understand him, and the feeling of 'will it ever be enough?' is always there. Right now I can't imagine a day where Autism isn't on my mind throughout the day, or an evening spent where I don’t look up things I've thought about during the day. If I don’t, I feel guilty. With all of the literature about the importance of intervention (early intervention in particular), the wait lists, and the hours needed versus the hours of therapy afforded (by families and government funding combined) it never feels like it will be enough - and with that comes a parental guilt that feels impossible to shake.”

> “To be honest I am exhausted. I haven't been able to say everything I would want to in this survey because I'm tired.”

> “I have to spend late night hours studying everything that can be of any help for my kids. Instead of sleeping and resting, I work an extra shift studying, searching, organizing, planning activities. I went back to college to better prepare myself to care for my kids since the therapies they need are not fully available.”

WHEN ASKED TO EXPAND ON HOW THEIR MENTAL HEALTH HAS BEEN AFFECTED BY NAVIGATING AUTISM-RELATED CARE, CAREGIVERS MENTIONED THE FOLLOWING *(IN ORDER OF FREQUENCY, n=251)*

- Anxiety-related concerns including stress, anxiety, worries, or uncertainty
- Feelings of being overwhelmed, lacking emotional or psychological capacity, mental exhaustion, or hopelessness
- Sadness-related concerns including depression
- Resilience, including internal abilities to cope, or external supports including therapists, physicians, mental health support programs
- Formal mental health diagnoses

“Being in and out of school due to COVID lockouts, then completely shut out of school since April 12, has taken an emotional toll on me. My child going to school daily was my respite and her need for autism support”

“Increased stress means I don't self-regulate as well as I should and may not support as well as I should. I get tired of always having to 'fight' for services, programs, and access to required resources and/or physicians.”

“J’ai de la difficulté à comprendre l’ensemble du programme et comprend ce qui est offert comme service. J’ai l’impression d’être dans un labyrinth.”

[TRANSLATION] “I have difficulty understanding the whole program as well as understanding what is offered in terms of service. I have the impression I’m in a maze.”

“J’ai besoin d’aide moi aussi.” *[TRANSLATION] “I myself also need help.”*

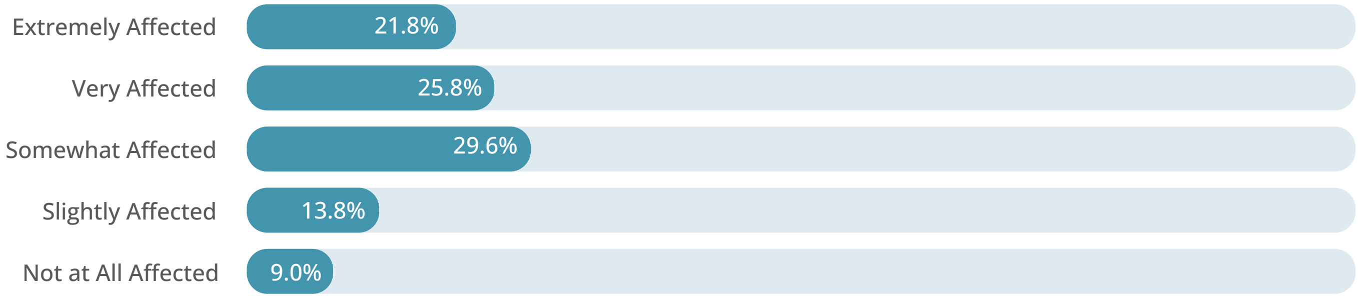
“The advocacy piece is truly exhausting and heartbreaking. Research tells us what kids need, yet as a parent I have to fight every single day for my son to get a fraction of what he needs.”

“As I'm the main caregiver most of my time goes to her, from 7:00am-8:30pm, then anything that arises during the night, many, many sleepless nights.”

“Advocating for 2 ASD children is a full-time job and parenting them is another full-time job. I have zero time for anything else.”

CAREGIVER PHYSICAL HEALTH

EXTENT TO WHICH CAREGIVERS FELT THAT THEIR PHYSICAL HEALTH HAD BEEN AFFECTED BY THE CHALLENGES OF ACCESSING AND NAVIGATING AUTISM-RELATED CARE *(n=1,727)*



This can be compared indirectly to the 2019 LARC Survey Report, in which caregivers were asked a slightly different question, about the extent to which their physical health was affected by "managing the stressors of autism in their family." Responses in that survey were as follows: 16% extremely affected, 29% very affected, 32% somewhat affected, 17% slightly affected, and 6% not at all affected.

Note: No statistical comparison was made because these two sets of results are from different sets of caregivers whose demographic makeup differ, as do the questions asked.

WHEN ASKED TO EXPAND ON HOW THEIR PHYSICAL HEALTH HAS BEEN AFFECTED BY NAVIGATING AUTISM-RELATED CARE, CAREGIVERS MENTIONED THE FOLLOWING *(IN ORDER OF FREQUENCY, n=258)*

Lacking capacity (time or energy) for physical self-care and resulting declines in physical health

Increased weight, stress eating, or problems with cardiovascular health (e.g., hypertension)

Pain- and autoimmune-related diagnoses, concerns or problems

Non-pain-related diagnoses

Sleep-related problems (e.g., insomnia, inadequate sleep due to parenting demands, anxiety disrupting sleep)

Reduced or lost ability to function, such as to care for their child, family, cope personally

“Advocating for your child is stressful. Guessing the best way forward is stressful. Taking time for research, when I could go for a relaxing walk or bike ride instead. Energy spent in the cooler, when I could spend it heating my family up to go outside together to have fun.”

"I am also autistic and struggle with my own mental health needs. It also brings a tremendous stress to the entire family. Feeling more isolated than ever before. No break or help.”

“It’s not easy to access mental health services or other services for adults, so I know I’ve started eating and drinking more to cope.”

“I’ve experienced physical health problems such has migraines, digestive problems, weight gain, scratches, bruises, bite marks and lack of sleep due to stress.”

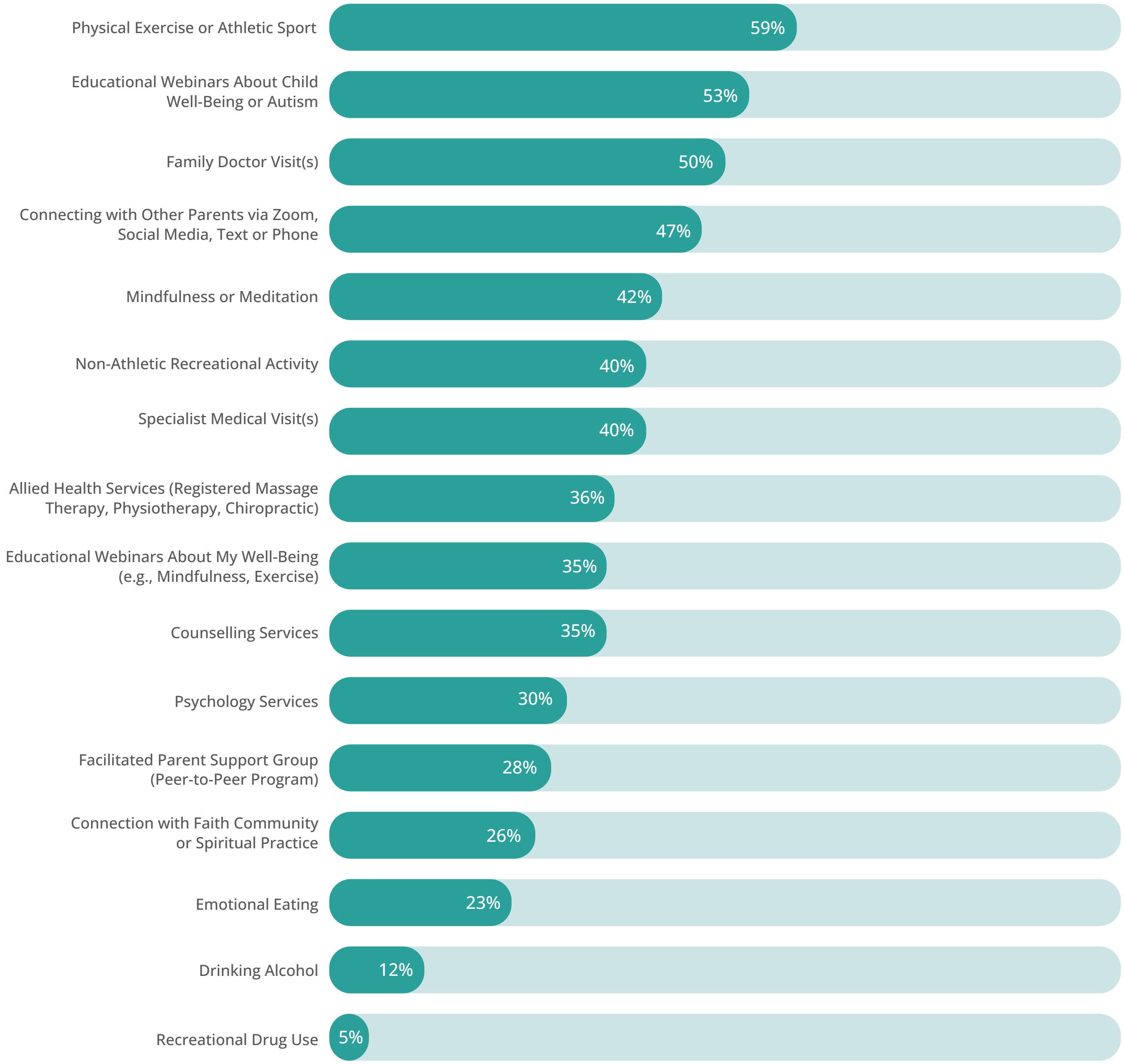
“I used to work out daily, cook all my meals from scratch, paint my nails, and take care of myself. Since my daughter's diagnosis, I am lucky to shower 2x a week, I never workout and I basically live off uber eats. I do not take care of myself at all.”

“I don't think that I have had a good night's sleep since 2010 when I first learned of my child's ASD diagnosis and thus, I entered the realm of parents with special needs children who, as physically strong as we all are, endure physical punishment from the stress loads placed upon us as a result of spending our time advocating for our children 24-7.”

CAREGIVER SELF-CARE AND SUPPORT

While a majority of caregivers reported partaking in healthy activities, such as exercise, to improve their health and well-being at least some of the time, a significant minority also described participating in activities that may be potentially harmful, such as drug and alcohol use, or emotional eating. Many caregivers acknowledged that they would benefit from more self-care, but could not find the time or the energy necessary to do so.

PROPORTIONS OF CAREGIVERS RATING DIFFERENT SUPPORTS OR STRATEGIES USED IN THE PAST AS HELPFUL TO RELIEVE THE EFFECTS THAT ACCESSING SERVICES (I.E., TIME COSTS, FINANCIAL COSTS, ENERGY COSTS, AND STRESS) HAD ON THEIR PHYSICAL OR MENTAL WELL-BEING *(n=1,867)*



CONCLUSIONS

High proportions of caregivers reported their level of stress in summer 2021 as moderately high (56%), or markedly high (approaching or in crisis: 8%). When asked to expand, caregivers mentioned multiple demands, such as combined childcare and work, and demands related to navigating or accessing autism-related care, as important sources of stress.

> *Many discussed not being able to prioritize their own well-being, due to time pressures or lack of services and supports.*

Caregiver mental health worsened for approximately 70% due to the COVID-19 pandemic, although some commented that their mental health had improved at the time of the study (July 2021) from earlier in the pandemic, when restrictions were higher and fewer supports were available.

Many caregivers identified the time that they spend advocating (average of 5.9 hours per week) and navigating care (9.3 hours per week) as a burdensome amount of work that contributes to stress. Sixty percent of caregivers indicated that their mental health had been very or extremely affected by the challenges of accessing and navigating autism-related care; and 48% indicated that their physical health had been very or extremely affected by the challenges associated with accessing and navigating autism-related care.

Many discussed not being able to prioritize their own well-being, due to time pressures or lack of services and supports. This suggests that solutions to caregiver well-being—both mental and physical—should address the high burdens that caregivers face in navigating and accessing autism-related care, which is known to be complex and span multiple systems.

FINAL THOUGHTS AND NEXT STEPS

A review of survey responses makes it clear that caregiver stressors that existed pre-pandemic and that were captured in the 2019 LARC Survey Report, such as long waitlists, difficulties navigating and affording therapies, and time stresses associated with accessing care, remain. These stressors were significantly compounded by the additional challenges that emerged over the study period, including isolation, and further service loss due to the COVID-19 pandemic, the ‘limbo’ and upheaval of the OAP over the past several years, and further waitlists to enter services, particularly core, needs-based therapy. Families facing crisis or mental health challenges often did not have access to the services they need, due to an ongoing lack of crisis and mental health supports.

The COVID-19 pandemic created unprecedented challenges for caregivers of children across society. COVID-related educational disruptions were particularly challenging for autism family caregivers, since school was not only the place where their children could access education, but was also a critical form of respite.

Furthermore, constant changes in routine were disruptive for these autistic students, many of whom faced additional challenges to engaging in online learning and loss of skills that they had previously obtained in the classroom. Caregivers struggled to keep their children engaged during remote learning while juggling multiple demands in their lives, including employment and the care of other children. Time and energy for self-care were often sacrificed, with notable impacts on caregiver mental health and physical well-being.

On the other hand, some families reported some unexpected advantages to remote learning, such as a lack of bullying or social pressures, and an increased awareness of their child’s actual level of achievement or style of learning. Those whose children were afforded the opportunity to continue learning in-person benefited greatly from these accommodations, while those who were not offered this option expressed much disappointment with this decision.

In the end, children are more likely to thrive when their caregivers are well supported. Likewise, caregivers are more likely to thrive when their children are well supported.

Families had mixed experiences with the OAP as well. Some caregivers appreciated the increased flexibility in spending options permitted through the OAP and other support programs during the study period. Limited OAP funding (provided in $5,000 or $20,000 allotments based on age) was helpful for many, and sufficient for some families, particularly those whose children have lower support needs. The small minority of children grandfathered in through the previous OAP benefited from the continuation of needs-based behaviour plans.

The majority of caregivers, however, indicated that the OAP did not meet their children's needs. For those whose children have high support needs, in particular, the amounts provided were a 'drop in the bucket,' and only enough to provide a few weeks or, at best, months of support. Others reported receiving no supports at all.

Parents often invested major personal economic resources to fill the gaps, sometimes creating economic strain or hardship in the process, while others could not afford to do so, so their children went without necessary services.

Other challenges, such as a lack of therapists, pandemic-related restrictions, and geographic and language barriers, were identified as additional obstacles to service navigation and access. In addition to autism-specific resources, caregivers reported a decrease in social and recreational pursuits and physical activity. All of these circumstances combined to negatively impact child and caregiver health.

Participating caregivers made it clear that they desire both needs-based services, as well as services with a minimal wait time. Many have waited for years to begin the therapy that they hope to receive for their children, and many commented that losing this time, particularly during "critical developmental windows", has caused them additional stress or guilt. For such families, needs-based wrap-around autism services, including not only therapy, but also respite, crisis and mental health supports, cannot come soon enough.

In the end, children are more likely to thrive when their caregivers are well supported. Likewise, caregivers are more likely to thrive when their children are well supported. Policies going forward need to consider both children and their caregivers within the broader family ecosystem, and urgently prioritize holistic and comprehensive services to optimize well-being and outcomes for both. We hope that this report can provide useful information for families, service providers, and policy-makers, to better understand caregiver and child needs, challenges, and aspirations at this critical juncture in autism policy reform.

On a final note, although this study succeeded in reaching a diverse cross-section of the Ontario caregiver population, we are also aware that certain populations, such as those who may not have regular internet access or who may not speak English or French, are likely under-represented in the data. Franco Ontarians are almost certainly under-represented, as we know that the proportion of respondents in this community are lower than for the province as a whole. In an effort to improve understanding of traditionally underserved populations, as a second part of this project, we are presently interviewing Indigenous and newcomer caregivers about the compounded challenges that they face. The results of this research, in addition to further findings and recommendations from the current study, will be posted on the LARC website (www.wlu.ca/LARC) once available.

APPENDIX A: LIST OF ACRONYMS

ABA	Applied Behaviour Analysis
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
EA	Educational Assistant
IEP	Individual Education Plan
IPRC	Identification, Placement and Review Committee
LARC	Laurier Autism Research Consortium
MPP	Member of Provincial Parliament
OAP	Ontario Autism Program
OT	Occupational Therapy
SEAC	Special Education Advisory Committee
SLP	Speech Language Pathology
SSAH	Special Services at Home
SSHRC	Social Sciences and Humanities Research Council

APPENDIX B: SUPPORTING ANALYSES

TABLE 1: VARIATION IN CHILD ENGAGEMENT IN ONLINE LEARNING BY AGE (GRADE LEVEL)

	Moderately or Well Engaged			Poorly or Not Engaged			
Child Age	n	% of Row Total	% Diff. from Expected	n	% of Row Total	% Diff. from Expected	Total
4	11	26%	-38%	31	74%	28%	42
5	30	27%	-37%	82	73%	27%	112
6	42	33%	-23%	86	67%	17%	128
7	41	33%	-22%	82	67%	16%	123
8	40	38%	-10%	65	62%	8%	105
9	36	35%	-17%	66	65%	12%	102
10	53	46%	9%	62	54%	-6%	115
11	46	52%	23%	42	48%	-17%	88
12	61	50%	18%	61	50%	-13%	122
13	47	46%	8%	55	54%	-6%	102
14	43	57%	33%	33	43%	-25%	76
15	36	54%	27%	31	46%	-20%	67
16	30	48%	14%	32	52%	-10%	62
17	40	63%	47%	24	38%	-35%	64
TOTAL	556	43%		752	57%		1308

Chi-Square (df)=504 (14), p<0.00001

TABLE 2: VARIATION IN SATISFACTION WITH EDUCATIONAL EXPERIENCE BY RACIAL/ETHNIC IDENTIFICATION

	Very Dissatisfied or Dissatisfied			Neither Satisfied nor Dissatisfied			Satisfied or Very Satisfied			
	n	% of Row	% Diff. Expected	n	% of Row	% Diff. Expected	n	% of Row	% Diff. Expected	TOTAL
White	461	46%	-2%	166	17%	-10%	377	38%	9%	1,004
Racialized	345	49%	3%	149	21%	14%	215	30%	-12%	709
TOTALS	806	47%		315	18%		592	34%		1,713

Chi-Square (df)= 11.48 (2), p=0.0032

TABLE 3: VARIATION IN SATISFACTION BY REMOTE VS. IN-PERSON LEARNING

	Dissatisfied or Very Dissatisfied			Neither Satisfied nor Dissatisfied			Satisfied or Very Satisfied			
	n	% of Row	% Diff. Expected	n	% of Row	% Diff. Expected	n	% of Row	% Diff. Expected	TOTAL
In-person only for both shutdowns	61	27.1%	-42.5%	34	15.1%	-16.9%	130	57.8%	66.5%	225
Remote learning only for both shutdowns	460	51.0%	8.2%	167	18.5%	1.9%	275	30.5%	-12.1%	902
Mix of in-person and remote learning	275	48.9%	3.8%	106	18.9%	3.8%	181	32.2%	-7.2%	562
TOTALS	796	47.1%		307	18.2%		586	34.7%		1,689

Chi-square (df)=63.91 (4), p<0.00001

APPENDIX C: AUTISM ONTARIO INFORMATION AND RESOURCES FOR CAREGIVERS

CHILD EDUCATION

KNOW YOUR RIGHTS

Students on the autism spectrum have rights. The Ontario Ministry of Education has enacted legislation and regulations to support the education of students with special needs. School boards are responsible for implementing programs in compliance with current legislation and regulations.

Students on the autism spectrum and their parents and caregivers must be actively engaged as full partners throughout the education process to optimize learning across home and school. Parents, caregivers, and students (where possible) play an active role, in partnership with educators, in all educational decisions.

Learn about Autism Ontario's Position Statements on Education (www.autismontario.com/autism-ontarios-education-position-statement). These are resources designed to help parents and caregivers resolve school issues, obtain needed educational supports or services, and help promote a change in the practices, policies and/or behaviours in our educational system in a respectful, positive and effective manner.

BE AN ADVOCATE

Education advocacy is about securing, protecting, and advancing your child's rights as a student in Ontario. Parents and caregivers may have to strongly advocate to ensure that their child's rights are met at school. It is a parent's/caregiver's right and responsibility to see that their child has an appropriate educational program, and it is certainly acceptable for parents and caregivers to advocate for their child.

A parent's/caregiver's relationship with the school/school board is not a social relationship. It is a business/legal relationship with the goal of getting the most appropriate education for your child.

Learn more about how to navigate the school system, including:

- Understanding your child's Identification, Placement and Review Committee (IPRC) (www.autismontario.com/programs-services/under-18/family-supports/school-supports/identification-placement-and-review)
- Knowing your role in the development of your child's Individual Education Plan (IEP) (www.autismontario.com/programs-services/under-18/family-supports/school-supports/individual-education-plan-iep)

- Advocating effectively while establishing positive working relationships with your child's school and teacher School Advocacy Toolkit (www.autismontario.com/programs-services/under-18/family-supports/school-supports/school-advocacy-toolkit)

ENGAGE POLICY AND DECISION MAKERS

Creating positive change begins with making our voices heard. Our collective voice can influence decision and policy makers.

- **Contact your local Member of Provincial Parliament** (MPP) to discuss your child's education to promote positive change. All MPPs maintain offices in both the provincial legislature and in their ridings and make time to meet with their constituents.
- **Learn how to effectively engage with key decision make**rs in Autism Ontario's Political Advocacy Toolkit, a non-partisan resource. (www.autismontario.com/programs-services/positive-advocacy-resources/political-advocacy-toolkit)
- **Call on the Ontario Government** to implement a new Autism Education Committee as recommended in the OAP Panel Report in the section with specific recommendations for the Ministry of Education. The Committee could meet virtually to achieve the identified outcomes of the report and consider new information contained in Findings from the *2020 Autism Ontario Education Survey*. (www.autismontario.com/sites/default/files/2020-07/Autism Ontario Readiness for School 30_7_20-1.pdf)

GET INVOLVED WITH THE SPECIAL EDUCATION ADVISORY COMMITTEE

Connect with – or become – your local SEAC (Special Education Advisory Committee) representative (www.autismontario.com/programs-services/positive-advocacy-resources/seac) through Autism) through Autism Ontario. Under the provincial *Education Act*, each school board in Ontario is mandated to have a SEAC, whose members are selected from volunteer representatives belonging to local groups such as Autism Ontario.

Each Autism Ontario region has a SEAC representative who liaises between the English and French public and Catholic school systems. Regional SEAC representatives are appointed for three- or four-year terms by the regional leadership council and the approval of the local school board.

CONNECT WITH AUTISM ONTARIO FOR MORE INFORMATION

For support with school-related issues, get in touch with Autism Ontario. Our Service Navigators and Regional staff can help guide you to your local school board's Special Education policies, procedures, and resources, and connect you with local advocates and workshops to help develop your advocacy skills.

- Contact your local Autism Ontario Region (www.autismontario.com/region)
- Connect with your regional Service Navigator (www.autismontario.com/programs-services/under-18/service-navigators)

AUTISM SERVICES, SUPPORTS, AND RECREATION

VIRTUAL AND HOME-BASED EVENTS & SOCIAL LEARNING OPPORTUNITIES

> Designed for children and youth on the autism spectrum and their families and caregivers, Autism Ontario's Social Learning Opportunities provide easy access to a supportive environment online and in their local communities. Find activities near you. (www.autismontario.com/events)

WEBINARS

> Autism Ontario webinars are interactive, easy-to-understand resources for parents, professionals, educators, and people on the autism spectrum. Webinars are presented in either English or French, by subject matter experts, in a discussion-based format. Watch our webinars. (www.autismontario.com/programs-services/webinars)

SERVICE NAVIGATION - CONNECT WITH OUR TEAM

Autism Ontario's Service Navigators and Regional staff provide information about the Ontario Autism Program and help connect families to service providers, programs, and resources available in their local communities.

> Connect with the Service Navigator (www.autismontario.com/programs-services/under-18/service-navigators) in your area

> Register for Service Navigation today (www.autismontario.com/civicrm/profile/create?gid=131&reset=1)

> Contact your local Autism Ontario Region (www.autismontario.com/region)

MENTAL HEALTH RESOURCES AND SUPPORTS

> Find your local Canadian Mental Health Association (https://cmha.ca/find-help/find-cmha-in-your-area/)

> Contact 211 Ontario (https://211ontario.ca/) to connect with information on and referrals to community, social, health-related, and government services or call 2-1-1

CAREGIVER WELL-BEING

Caregiving can be a uniquely rewarding experience, while at the same time mentally and physically exhausting. Caregivers of children and youth on the autism spectrum often report elevated levels of stress and social isolation. The joys and responsibilities of parenting a child on the autism spectrum can demand an incredible amount of time and care from parents. Many self-care and mindfulness evidence-based strategies, such as stress management, helpful thinking, self-compassion, and problem solving, have been shown to improve mental health outcomes.

CARING FOR CAREGIVERS

- Autism Ontario’s webinar series in partnership with the South Asian Autism Awareness Centre (SAAAC) on building resilience is a series of four short webinars covering key skills such as self-care, mindfulness, self-compassion, and assertive communication to better support caregivers through their day-to-day challenges. Watch today (https://onlinexperiences.com/scripts/Server.nxp?LASCmd=AI:4;F:APIUTILS!51004&PageID=2FE0A0AF-8432-4126-A164-262CFA33D175&fbclid=IwAR1W9vnLPMTi6xzrZL1nEhAcl6nRrR8Q7bMiwlOey0BfPUWF-13A2qR_VG0)

ONLINE SUPPORT GROUPS

- Connect with caregivers in one of Autism Ontario’s online support groups, including the Black Caregiver Check-in & Chat, South Asian Check-in & Chat, New Diagnosis Support Group, and others. These groups provide an opportunity to come together, learn, and share experiences. Register today. (www.autismontario.com/events?custom_325=All&event_type_id=20)

CARES CAREGIVER SUPPORT PROGRAM

- The SAAAC CARES Caregiver Support Program (www.autismontario.com/events?custom_326=All&custom_325=All&event_type_id=28&custom_356=All) is an innovative, group-based intervention targeting the social, emotional, and psychological challenges that can arise among caregivers of children on the autism spectrum. CARES provides a safe space for caregivers to share their experiences and develop a sense of shared identity.

- CARES is offered primarily as a virtual program and is available to parents and caregivers across Ontario throughout the year. If you are interested in joining an upcoming session, please complete this interest form and Autism Ontario will send you program information when it becomes available. (https://forms.office.com/Pages/ResponsePage.aspx?id=DFpPRRE61Ea1EsbGBcuXNfs9u9-1RfdCnl2S32gFlx5UQUhXUEZGTFNDMVdGVEVXQVA4TEtJOTJISC4uO)

ADDITIONAL MENTAL HEALTH RESOURCES AND SUPPORTS FOR CAREGIVERS

- Canadian Mental Health Association (Ontario) Family and Caregiver Support resources and services. (https://ontario.cmha.ca/documents/family-and-caregiver-support/)

- CAMH Patient and Family Engagement (https://www.camh.ca/en/your-care/for-families)