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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EXECUTIVE SUMMARY

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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.

To access the full report and related resources, please visit: www.wlu.ca/LARC