

TOP 5 PRIORITIES FOR FAMILIES AND SELF-ADVOCATES IN ONTARIO

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INTRODUCTION

Autism Ontario conducted an annual province-wide survey to gain a better understanding of the current needs and experiences of caregivers and autistic adults.

In the past, Autism Ontario has relied on professional expertise to determine the most important, actionable items from the data.

This year, in order to more accurately pinpoint what the autism community itself believes to be the most pressing and important areas for action and study, we conducted a secondary survey so the community could rank the results in order of perceived importance.

This poster will detail and explore the top 5 priorities as ranked by the community.

METHODS

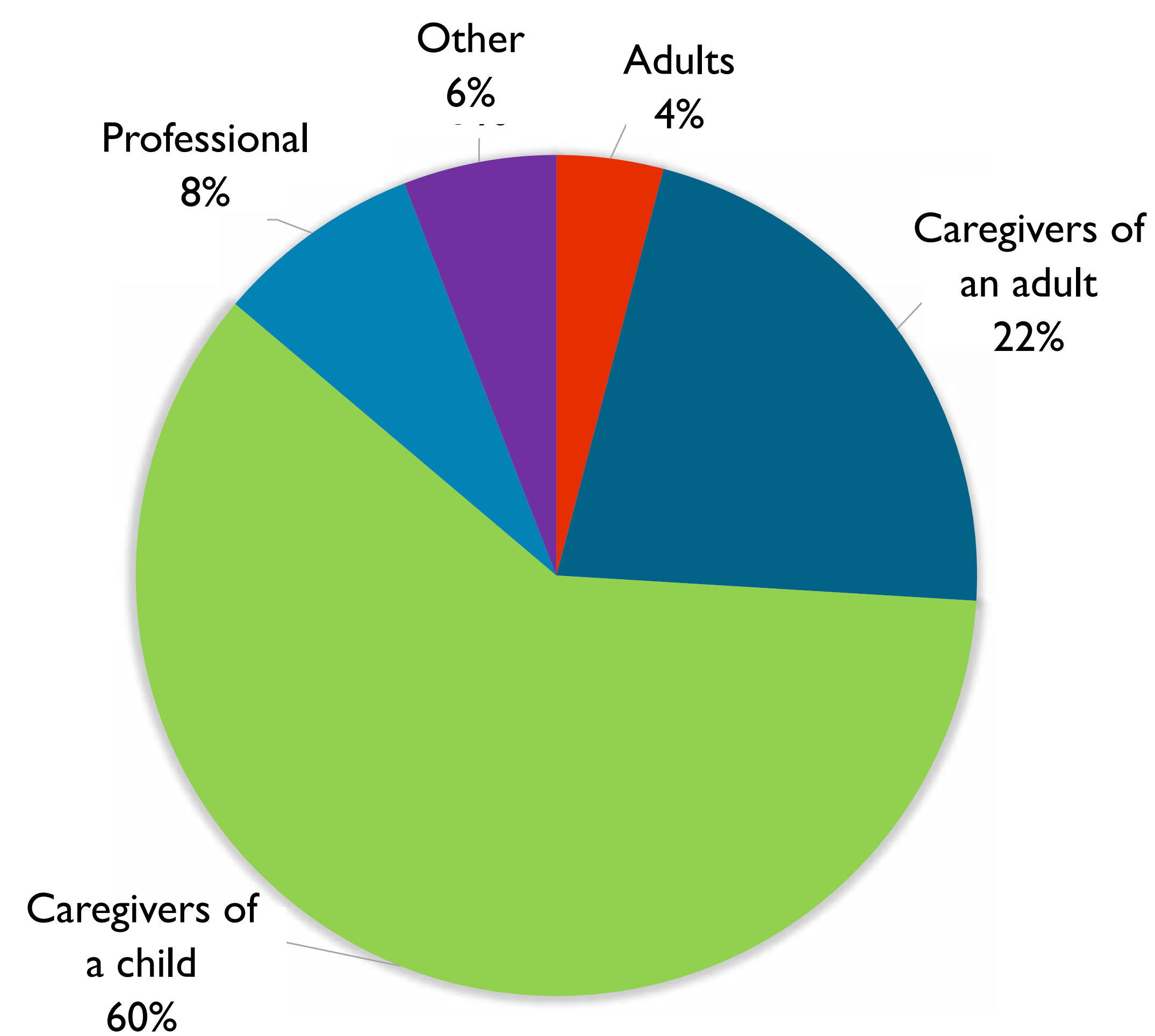
The initial survey was developed by a team at Autism Ontario in consultation with external stakeholders. It was available in French and English and was open for the month of May, 2018.

Respondents

- 1,514 caregivers
- 87 autistic adults

Autism Ontario then sent out a secondary ask to the broader community for people to rank the information in terms of what they felt was most important to them.

Respondents 2nd Survey



RESULTS

The autism community identified the following as the top five issues to highlight as priorities.

#1 Education Support



Education support was rated the highest area of need, though 69% of caregivers of elementary school and 77.8% of caregivers of high school aged children, strongly agreed or agreed with the statement “**We feel listened to by our child’s school.**”

#2 Long Waitlists



73.6% of caregivers reported long waitlists as the largest barrier to service, with respondents classifying waitlist as a **large (23.9%) or very large barrier (49.7%)**.

60.3% of adults reported long waitlists as a **large (20.6%) or very large barrier (39.7%)** to accessing service.

#3 Financial Hardship



56.3% of caregivers said that finances had being a **large (23.9%) or very large (32.4%) source of stress** in the past year.

50.7% of autistic adults said that finances had being a **large (23.4%) or very large (27.2%) source of stress** in the past year.

#4 School Transitions



87.4% of caregivers say it is very stressful to plan for their child’s transition out of school and **83% reported not feeling well supported or ready to do so.** 59.2% are not confident the transition out of high school will be smooth.

#5 Adult Services



For autistic adults, a **lack of necessary services** and a lack of **professionals who understand autism** are the largest barriers to service, with **63%** of adults identifying these as large or very large barriers. The top identified service need was psychological or psychiatric support.

Other data points not selected:

1. Societal attitudes and perceptions – Autistic adults and caregivers said that societal attitudes and perceptions about ASD had being a large/very large source of stress in the past year.
2. Under 4 service needs – The top identified service needs for children under 4 were behavioural intervention and speech language pathology.
3. Crisis status – The majority of caregivers said they were between a three and a five out of ten in terms of crisis level.
4. Mentorship and support – Caregivers reported large scale interest in receiving peer support via a parent to parent mentorship program.
5. Mental Health – Autistic adults identified their top service needs as psychological or psychiatric support.

FUTURE DIRECTIONS

- The top 5 priorities described in this poster detail areas of significant need and hardship for the autism community in Ontario.
- The findings point to a need for further support in the education system, health care system as well as a need for continued financial investment into autism services in the province.
- Researchers and policy makers should look to the autism community to help inform areas for further study and investment.
- Participatory research and community engagement is critical in order to better support individuals and their families.