



Autism Ontario's 2014 Province-Wide Survey: Summary

Introduction

In the summer of 2014 Autism Ontario sent out a province-wide survey to 9,000 families and practitioners. The goal was to solicit feedback on a range of issues related to Autism Ontario and identify needs within the ASD community.

We received responses from approximately 1,560 individuals representing all 25 chapter regions.

Caregiver of a child with ASD: 76%

Caregiver of an adult with ASD: 22%

Individuals with ASD: 2%

Autism Ontario members: 58%

Francophones: 11%

Aboriginal Community – 2%

Professionals – 18%

The survey included two open ended questions which asked respondents to list services they wanted offered and areas of need they hoped would be addressed. There were several overarching themes, including a need for more funding and a need for services in rural areas. Listed below in order of mention, are the four most frequently cited topics and the needs identified within each. Included are a brief summary and representative comments.

Adult Supports

Overall, the most prevalent concern surrounded supports for adults. In general, individuals spoke about a lack of resources, and reported feelings of despair and confusion once their children turned 18 and thus were no longer eligible for the services they had come to rely upon. Specifically, responses centered on a need for more programs and supports of all kinds, in both urban and rural areas.

"No funding, no programming, it's like they drop off a cliff when they leave school."

1. The issue raised most often in the data was a need for support and training in relation to employment and daily living. This included a call for vocational training, daily living skill acquisition, job coaching and help finding employment opportunities.

"...it would be very effective in terms of vocational planning to have comprehensive 'life skills' i.e. ability to live independently, secure a job, obtain driver's license, etc."

2. The second most discussed issue concerned the difficulty families face when it comes to finding adequate and inclusive housing for their adult children.

"...needs to be more effort put into finding solutions and providing awareness to the current housing crisis. I don't want my child to be living in sub-standard conditions, at risk for being abused or assaulted. I want to know when I die that my child will be taken care of."

3. The third most prevalent issue was a call for social skills training programs specifically for adult populations.

"Social Skills training program such as PEERS for adults. Young adults and also older, with separate groups. Just because you turn 18 does not mean you no longer need training and assistance."

It is worthwhile noting that these concerns surrounding adulthood were not only voiced by adults or parents of adults, but also by parents of children who are worried about what will happen to them as they age.

"Our kids are growing up, they will become adults that will have very little support and resources."

Teens and the Transition to Adulthood

The second most discussed topic was teens and the transition to adulthood. In a similar vein to the adult comments, it appears as if there is a strong need for additional services. This includes both daily living skills programs and social skills training.

1. The most frequently mentioned issue was a general lack of focus on teens and a need for more support across a wide range of areas, both in terms of skills training and educational opportunities.

"Services seem to be tailored for panicking parents of preschool aged children, whilst parents of teens and older children are left out in the cold. I hate to see how it's going to be once my child is an adult."



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- In addition to a desire for more programs and supports for all types, the most common request was services to support teens' transition to adulthood. This included a call for daily living skills, co-op placements and help transiting teens out of high school.

"There needs to be services and information when teens transition to adults. I want peace of mind that my son will continue to have supports as he gets older and can work toward independence in the future."

Interventions

The third most commonly discussed topic was ABA and therapies, both as they relate to early behavioural interventions and services within the school system.

- The majority centered on concerns related to a lack of funding and subsequent long waitlists.

"We were told by public funded services such as (autism service provider) that we should re-mortgage our home to pay for private ABA/IBI services if we don't like the waiting lists."

The second most commonly mentioned need was the strong desire for more ABA and more services across the lifetime. Often cited was frustration over the lack of available behavioural resources for older children and confusion over eligibility as it related to age.

"I would like to see one on one ABA services for children who have aged out of TPAS. NOT the group classes but one on one even if it was only once a month."

- The third most prevalent concern was in regards to accessibility based on geographic region.

"Parents are struggling to access services in our rural area but don't have the ability, or even where to start."

- And finally, the lack of supports within the education system and a desire for more comprehensive continuity and integration of services between educators and service providers.

"Why do our children who have worked hard and made great strides through their IBI program have to take 20 steps backwards in the public school system because the teachers are unqualified and basically view them as someone that cannot learn."

Family Supports

The fourth most discussed topic was family support. This covered a wide range of needs listed below, once more comments centered on a need for accessible, affordable services offered province-wide.

- The most frequently mentioned need was for information resources and support – a desire for more educational resources, webinars, workshops, training and help!

"I spend a lot of time hunting down individual resources to support my child...It would be ideal if each person with ASD was assigned a specific case manager/co-ordinator/counsellor who could keep in contact with families and update them on opportunities and options..."

- The second topic discussed in relation to family supports was a desire for more family and community programs, including sibling groups, family activities and specialized camps.

"Parenting support groups and family events - like movie screening with the sound turned down, art programs for kids of all ages, etc..."

- Lastly, tied in with many of the programs and supports was a call for more respite care. Many respondents mentioned both a lack of access, due to financial constraints or regional availability, and a lack of quality-checked workers.

"Respite care services is a hit and miss, the people I found were not able to stash their cell phone away and interact with the child...need serious overhaul to respite services along the type where parents can find nearby available help."

In Summary

Across the board, there was an outcry for more funding, more resources and pleas for help navigating an already challenging issue. Based on geographic location, it seems parents and caregivers often feel unheard and underserved, and hope for access to additional programs and supports.

"There's no central agency for autism. You search and ask, and search and ask - and maybe you find some help."

"We cannot simply be told to wait for the research to catch up. We will all be dead by then."

