THE OAC COMMUNITY SURVEY REPORT 2025

PREPARED BY

THE ONTARIO AUTISM COALITION

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ONTARIO AUTISM COALITION

ACKNOWLEDGEMENT

The Ontario Autism Coalition (OAC) extends their heartfelt gratitude to everyone who took the time to participate in this community survey and share their experiences. Your voices are the foundation of our work, and your courage in sharing your stories helps us illuminate the challenges faced by autistic people and their families across Ontario.

Every response strengthens our collective advocacy, guiding our efforts to demand meaningful change and ensure that all individuals and families in the disability community receive the support they need when they need it. Your insights are invaluable, and together we will continue working toward a system that truly respects the dignity and rights of every individual.

Thank you for your trust, honesty, and commitment to this shared cause.
We couldn't do this without you.

ONTARIO AUTISM COALITION

START HERE

CAUTION

Before you begin reading:

We want to take a moment to acknowledge the sensitivity of the topics covered in this report. The Ontario Autism Coalition Community Survey (2025) explores deeply personal and often difficult experiences, including barriers and delays in accessing vital services, the impact of inadequate supports, and the toll these challenges can take on mental health and well-being.

Some of what you will read may be upsetting or emotionally difficult. Please take care of yourself as you move through these pages. If at any point it feels like too much, we encourage you to pause and return when you feel ready, ideally in a space where you feel supported and safe.

If you are in distress or need someone to talk to, please reach out for support. You can find resources here:

Government of Canada: Mental Health and Wellness Resources
https://www.canada.ca/en/public-health/services/mental-health-services/mental-health-get-help.html

CAMH
https://cmha.ca/

Mental Health Research Canada
https://www.mhrc.ca/mh-resources

While this report reflects painful realities, it is also rooted in hope and solidarity. Families and individuals from across Ontario came together to share their stories, not for themselves alone, but to help create change for everyone. This collective effort is an act of strength, resiliency, compassion, and determination to build a better, more inclusive society for everyone.

A Note on Language:

In this report, we use the terms “autistic person/people/individual”. This choice reflects the guidance of self-advocates on our Board of Directors and the wider community who have expressed a preference for identity-first language.

However, we recognize that language preferences are personal and diverse. Some individuals prefer person-first language (e.g., “person with autism”), and it is always best to ask and follow each person’s preference in conversation or writing.

Our goal is to reflect respect, dignity, and inclusion in the way we communicate and to honour the voices of those at the heart of this work.

WHO WE ARE

The Ontario Autism Coalition (OAC) is a grassroots, non-partisan, political advocacy organization dedicated to advancing the rights, inclusion, and well-being of autistic individuals and their families in Ontario, Canada. Founded in 2005, the OAC works tirelessly to advocate for timely, equitable access to services, support, and education for autistic individuals and their families throughout their lives.

The coalition is comprised of volunteers who are self-advocates, families, educators, service providers and allies united by a shared commitment to systemic change. This volunteer power operates on the principles of collaboration, empowerment, and evidence-based advocacy, engaging with policymakers, community partners, and the broader community to drive meaningful improvements in areas such as:

- The Ontario Autism Program (OAP): Advocating for timely, needs-based services and funding for families.
- Education: Promoting appropriate accommodations that ensure meaningful education and school safety for students and educators.
- Adult Services: Promoting timely, needs-based services and support for those over 18 years of age.
- Community Safety: Ensuring families have the tools they need to live in and advocate for safe communities.

The OAC uses a combination of public awareness campaigns, government consultation, and community engagement to push for accountability and justice. It also amplifies the voices of those affected by systemic failures, ensuring that their experiences inform policy solutions.

The organization's core belief is that autism is lifelong, and every individual deserves the opportunity to lead a life of dignity, inclusion, health, and full potential.

MISSION

To secure permanent, evidence-based, government-funded services for autistic people and their families (2025)

ONTARIO AUTISM COALITION

EXECUTIVE SUMMARY

The 2025 Ontario Autism Coalition (OAC) Community Survey provides an in-depth look at the experiences, challenges, and priorities of autistic individuals and their families when accessing, or trying to access, services in Ontario. The survey offers powerful evidence of persistent systemic failures and the urgent need for increased capacity and funding in provincial services to meet the needs of the community, particularly within the Ontario Autism Program (OAP), education, and respite systems.

Purpose and Scope

This year's survey sought to measure progress since previous OAC community consultations and to document the continued impact of existing systems on families. It aimed to:

- Identify service access barriers within the OAP and related systems.
- Capture community experiences with education, mental health, and respite support.
- Inform advocacy and public policy priorities for 2025–2026 and beyond.

Methodology

The survey was distributed province-wide and open to autistic individuals and their families. Responses were collected through SurveyMonkey in June 2025, yielding over a thousand submissions. Respondents represented all regions of Ontario, spanning urban, suburban, rural, and northern communities.

Key Findings

- Systemic Failure of the OAP: The majority of respondents reported that the OAP continues to be inaccessible and inequitable. Waitlists remain years long, and funding levels do not reflect actual needs.
- Escalating Family Crisis: Families described growing desperation, with some turning to Children's Aid Societies due to a lack of services.
- Education System Gaps: Respondents highlighted widespread exclusion from classrooms, inconsistent access to educational assistants, and systemic failures in special education supports.
- Respite and Mental Health Shortages: Many caregivers reported burnout and an absence of affordable, quality respite services.
- Regional Inequities: Northern and rural communities continue to face the most severe shortages in specialized services and professional support.
- Community Resilience: Despite these barriers, respondents expressed strong mutual support and solidarity, underscoring the OAC's role as a key advocacy voice.

Insights and Interpretation

The survey reveals that government reforms have failed to address the crisis families are facing. Data show that, in particular, the OAP "needs-based" model is neither fully functional nor responsive to the realities of autistic children, youth, and families. Families report worsening conditions since 2023, reflecting a deep erosion of trust in public systems.

Conclusions and Recommendations

The OAC calls for:

1. Immediate emergency government funding must be directed to enhance the core clinical services program and get children and youth off the waitlist for consistent care, with spending prioritized for direct therapy services rather than administrative costs.
2. Transparent, needs-based core clinical funding aligned with clinical recommendations, that increases with inflationary costs.
3. Accountability and transparency from the Ministry of Children, Community and Social Services.
4. Pillar programs should be re-evaluated as some are too narrow, unethical, costly, and serve too few.
5. Meaningful special education investments, ensuring a needs-based approach with appropriate staffing and accommodations.
6. Investment in respite and mental health infrastructure for children, youth, and adults.

Next Steps

Findings from this survey will guide the OAC's 2025 advocacy agenda, upcoming legislative engagement, and public awareness campaigns. The coalition will use these data to continue amplifying the voices of families and to press for systemic accountability, transparency, and justice for autistic Ontarians.

EXECUTIVE SUMMARY

DEMOGRAPHICS

1:32
2025 EST ASD Prevalence in Ontario (0-18)
*UNDERESTIMATE: SEE APPENDIX A.

1,007
TOTAL Study Sample

3-9
AVE AGE OF DIAGNOSIS

91%
Identified as parent of someone 18 and under

ONTARIO AUTISM PROGRAM

906 → **224** = **24.7%**

Study Sample Registered to the OAP

Accessing CCS Funding

Of OAP Registered Accessing CCS

13.5
Average age of children/youth with access to core clinical services funding

PILLAR PROGRAMS

ENTRY TO SCHOOL
19%
ACCESSING AT THE TIME OF THE SURVEY

URGENT RESPONSE
17%
ACCESSING AT THE TIME OF THE SURVEY

FOUNDATIONAL SERVICES
13%
ACCESSING AT THE TIME OF THE SURVEY

Caregiver Mediated Early Years
9%
ACCESSING AT THE TIME OF THE SURVEY

At the time of the survey, 326/906 (36%) OAP-registered children and youth were accessing AT LEAST one OAP component (a pillar program or CCS).

Based upon known OAP registration at the time of the survey (approx 80,998) we know 29,155 (not 45,000) children and youth were accessing at least one OAP service.

*CAVEAT: PILLAR PROGRAMS DO NOT OFFER THE SAME COMPREHENSIVE SUSTAINABLE SERVICES THAT CCS DOES - THEY ARE NOT A SUBSTITUTE. ALSO: HAVING ACCESS TO CCS FUNDING DOES NOT NECESSARILY MEAN A FAMILY HAS ACCESS TO SERVICES TO PURCHASE.

ABA

75%
SAW ABA PRICE INCREASE IN THE LAST YEAR

57% reduced therapy hours because of price increase

RESPITE

44%
WAITLISTED

83%
say support doesn't meet needs

SCHOOL

47%
LACK NEEDED ACCOMMODATIONS

9% not attending full time due to lack of resources

CAS

8.8%
CONTACTED CAS DUE TO A LACK OF SERVICES and/or SUPPORT

FINANCIAL STRAIN

Many families reduce work hours or incur debt to fund care

44%
Of children/youth live in a household where at least 1 family member is caregiving full-time

ONTARIO AUTISM COALITION

METHODS

The Ontario Autism Coalition (OAC) Community Survey (2025) gathered insights into the experiences of individuals across the autism community in Ontario, including children, youth, adults, and their families. The survey captured experiences with services across the lifespan, including diagnosis, the Ontario Autism Program (OAP), adult services, education, respite, mental health supports, barriers to care, and open-ended narrative responses.

The cross-sectional survey was open to anyone in the autism community and disseminated broadly to try and capture participation from families, caregivers, and autistic individuals across the province. Due to its extensive circulation through similar autism-focused community channels, responses may reflect a significant representation of the OAC autism community (a younger cohort was observed). The sampling approach mirrored previous OAC surveys, using a combination of convenience sampling and snowball sampling:

- Convenience Sampling: Responses were collected from readily accessible groups, including followers of OAC social media pages, mailing lists, and community networks. Participants were selected based on ease of access rather than random selection.

- Snowball Sampling: Participants were encouraged to share the survey within their networks, allowing the sample to grow organically through community connections.

Both methods are non-probability sampling techniques, meaning the results may not be fully representative of the entire autism community in Ontario. However, they are widely used in advocacy and community-based research to reach specific populations that are otherwise difficult to sample randomly.

The survey was available via SurveyMonkey from June 7 to June 30, 2025, and received a total of 1,040 responses. After data cleaning to ensure eligibility and integrity, 1,007 responses were included in the final analysis. This sample size exceeded the minimum required for statistical representativeness, assuming a large population and a 95% confidence interval with a 5% margin of error. Respondents represented families and individuals across all regions of Ontario. To determine whether differences between two independent estimates were statistically significant or not, the associated 95% confidence intervals were compared. Non-overlapping 95% confidence intervals between estimates were considered statistically significantly different.

Analyses were performed in R version 4.5.1 (R Core Team, 2025) using the RStudio IDE (RStudio Team, 2023).

To protect participant anonymity, response totals of fewer than five were suppressed.

PURPOSE

The Ontario Autism Coalition's Community Survey exists to put truth and power back in the hands of families. Too many are still waiting for Core Clinical Services funding, for transparency, for change. Families deserve to know what's really happening, not be left in the dark. So instead of waiting for the government, we decided to tell our story ourselves. This survey is part of our data journey, reclaiming our narrative, strengthening our collective voice, and showing in real time how families are actually experiencing the services landscape in Ontario.

RESULTS
DEMOGRAPHICS

Describing a survey population is essential to provide context for the findings and to ensure the results are interpreted accurately. It helps readers understand the scope, limitations, and potential biases of the data, enabling a clearer assessment of how representative the results are of the broader community. This section describes the population of Ontario residents that are represented in these survey results.

Respondents: Who took the survey?

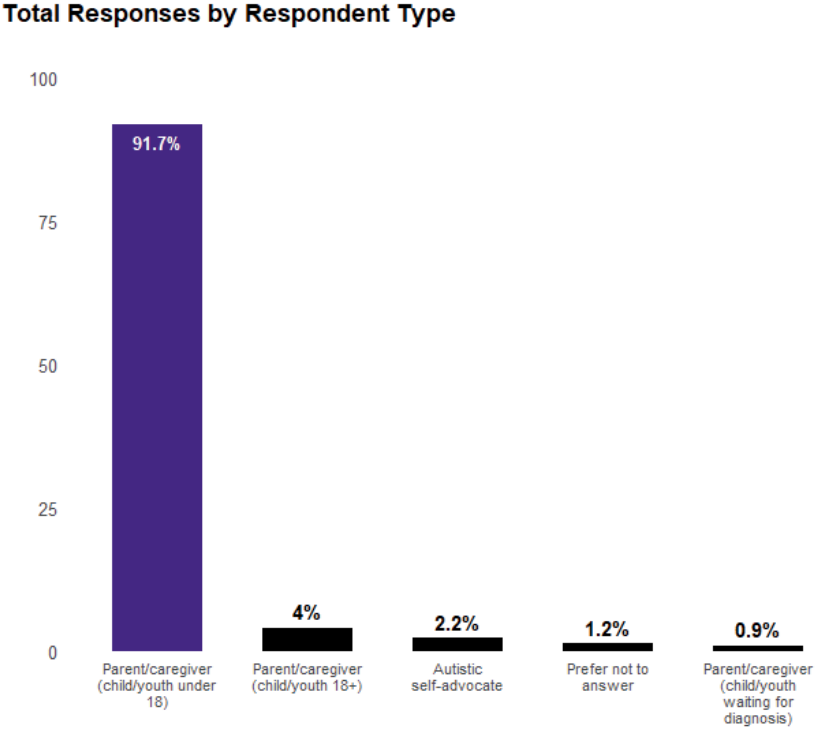
Which best describes you?

This question asked respondents to identify the group that best describes them. This information provides important insight into respondents' perspectives, indicating whether they completed the survey for themselves or on behalf of a family member. It also adds context to the analysis by highlighting respondents' positions in their journey and showing how different groups experience services.

Almost all respondents (91.7%) identified as parents or caregivers of a child or youth under 18 waiting for or accessing the Ontario Autism Program (OAP). Smaller proportions included autistic self-advocates (2.2%), parents of someone over 18 (4%), and parents of a child or youth waiting for an autism diagnosis (0.9%). In the open-ended portion of this question, many also described themselves as autistic parents of autistic children; a perspective not fully reflected in the closed categories provided, but important to acknowledge.

These data likely reflect the demographic makeup of families who access our OAC community and partner organizations, many of whom have younger children. These variations should be considered when interpreting the results.

FIGURE 1: The majority of respondents reported being a parent/caregiver to an autistic child/youth (18 and under) waiting for or accessing the OAP



RESULTS
DEMOGRAPHICS

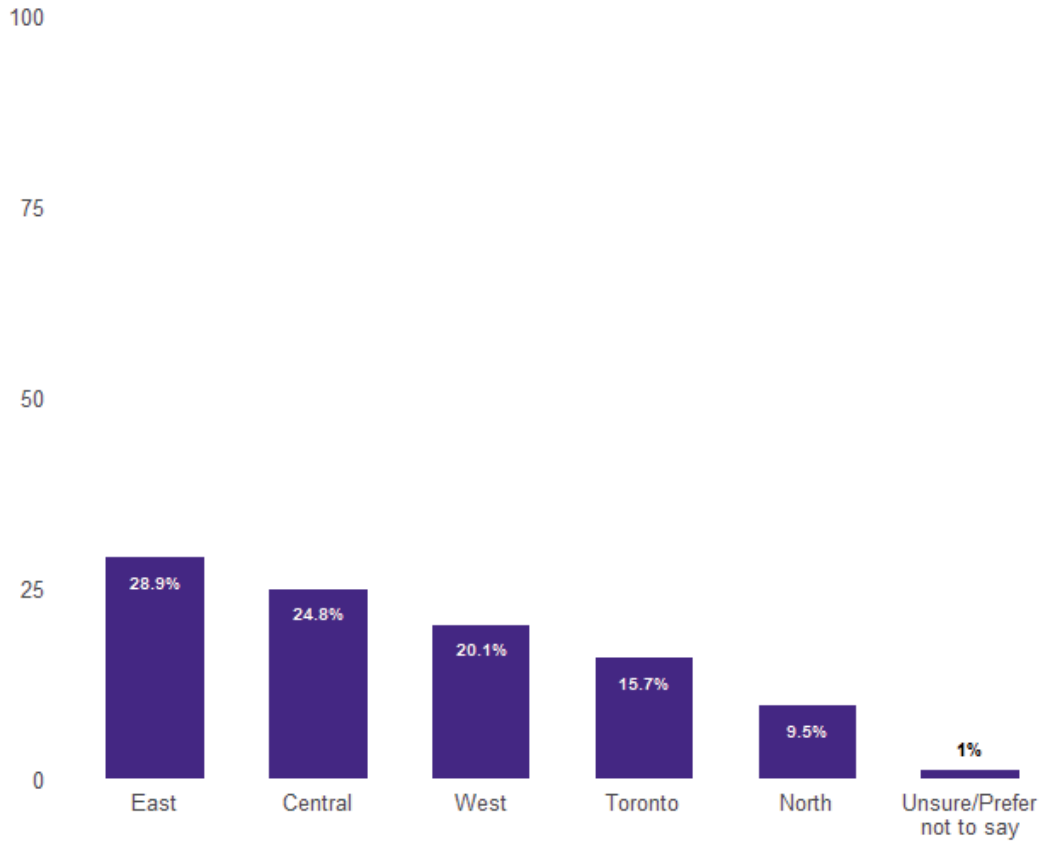
Respondents: Where were they from?

Which OAP region do you live in?

It is important to interpret these results through a regional lens, as access to services can vary widely across the province. This question asked respondents where in Ontario they reside. For this analysis, regions were defined according to the Ministry of Children, Community and Social Services' service delivery areas: East (28.9%), Central (24.8%), West (20.1%), Toronto (15.7%), and North (9.5%) (1).

Region is used as a stratifying variable throughout this analysis to explore if there are any regional differences in service experience.

FIGURE 2: The majority of survey respondents reported residing in the Southern Ministry of Children, Community and Social Services service delivery regions

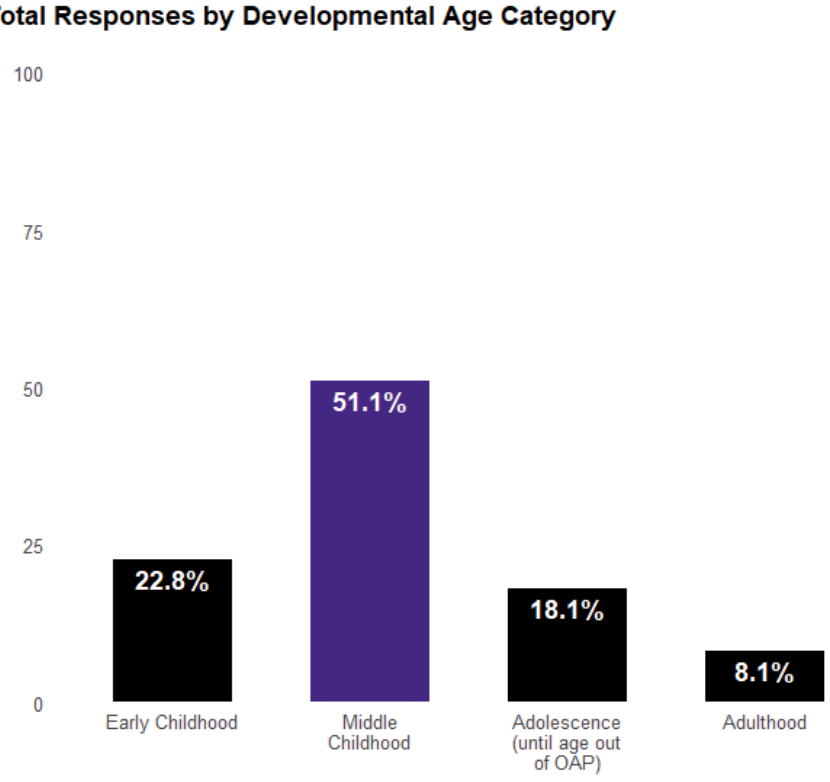


RESULTS
DEMOGRAPHICS

Age distribution of the survey demographic:

The survey captured responses about autistic people from across a range of life stages, with the largest proportion representing children in middle childhood (51%), followed by early childhood (23%), and adolescence (18%). A smaller share of responses came from or about autistic adults (8%). This distribution reflects the Ontario Autism Coalition's reach within the autism community and highlights that the majority of respondents are families currently engaged with the Ontario Autism Program (OAP) or approaching the transition out of it. The inclusion of adults on the autism spectrum provides important insight into the lifelong nature of support needs and the ongoing challenges of accessing appropriate services across the lifespan.

FIGURE 3: More than half of the autistic people described in this survey were in the middle childhood category at the time of this survey



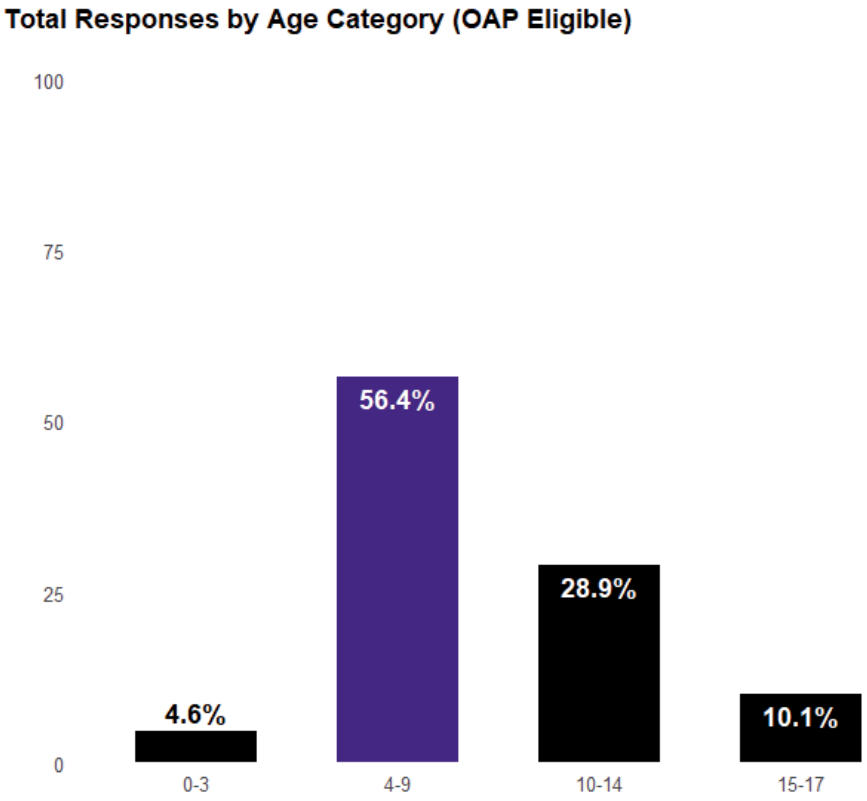
RESULTS
DEMOGRAPHICS

Age categories of the Ontario Autism Program eligible survey demographic:

The majority of survey respondents represented children in the 4–9 age group (56%), followed by those aged 10–14 (29%). A smaller proportion were in the 15–17 age range (10%), and very few were under the age of 3 (5%).

These age categories align with the Ministry of Children, Community and Social Services' (MCCSS) groupings for eligibility within the Ontario Autism Program (OAP) Core Clinical Services framework (2). This distribution suggests that most families engaging with the survey are those currently navigating, or soon to be navigating, the Core Clinical Services component of the OAP, a stage where service access, funding, and coordination are often most critical.

FIGURE 4: More than half of the autistic people who were OAP eligible at the time of the survey were in the 4-9 year age range (OAP Funding Categories)



RESULTS
DIAGNOSIS

Does the person you are filling out this survey for have an autism diagnosis?

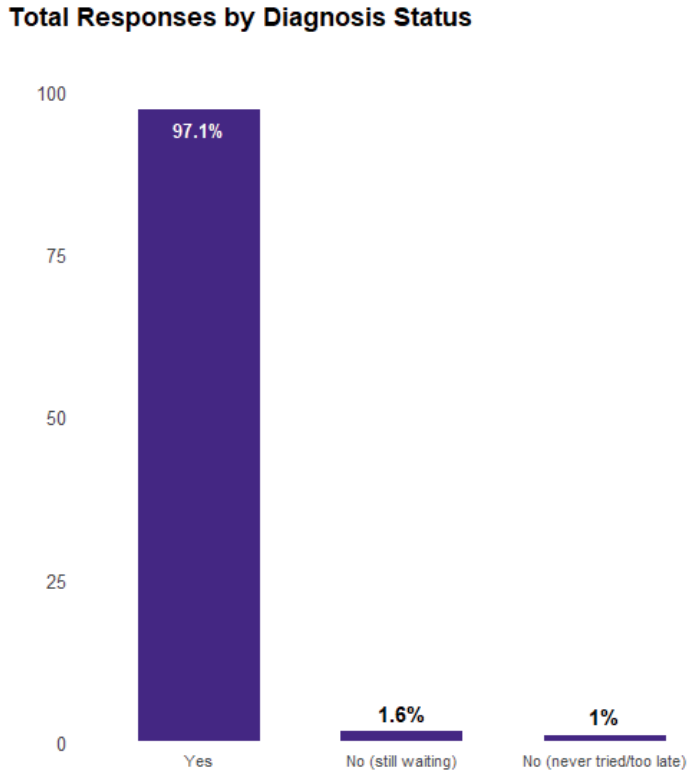
This question asked respondents if the person they were filling the survey out for has an autism diagnosis.

The fact that so many have a diagnosis describes the OAC population very well, as most families seek the Ontario Autism Coalition out after diagnosis, when they are looking for community support during the wait for services.

Those still waiting for a diagnosis (1.6%) cited the following reasons for the delay (in order of proportion):

- Waitlisted at a provider for diagnosis
- Other (very specific circumstance)
- Waiting for a specific age
- Too expensive
- No providers available in their region

FIGURE 5: The vast majority of autistic people described in this survey have a formal autism diagnosis



RESULTS

DIAGNOSIS

How long was the wait for a diagnosis?

This question asked respondents how long they, or their child/youth, had to wait for an Autism diagnosis. While the majority received a diagnosis within a year (63.1%), approximately one-third of those represented in this survey waited over a year (32.8%).

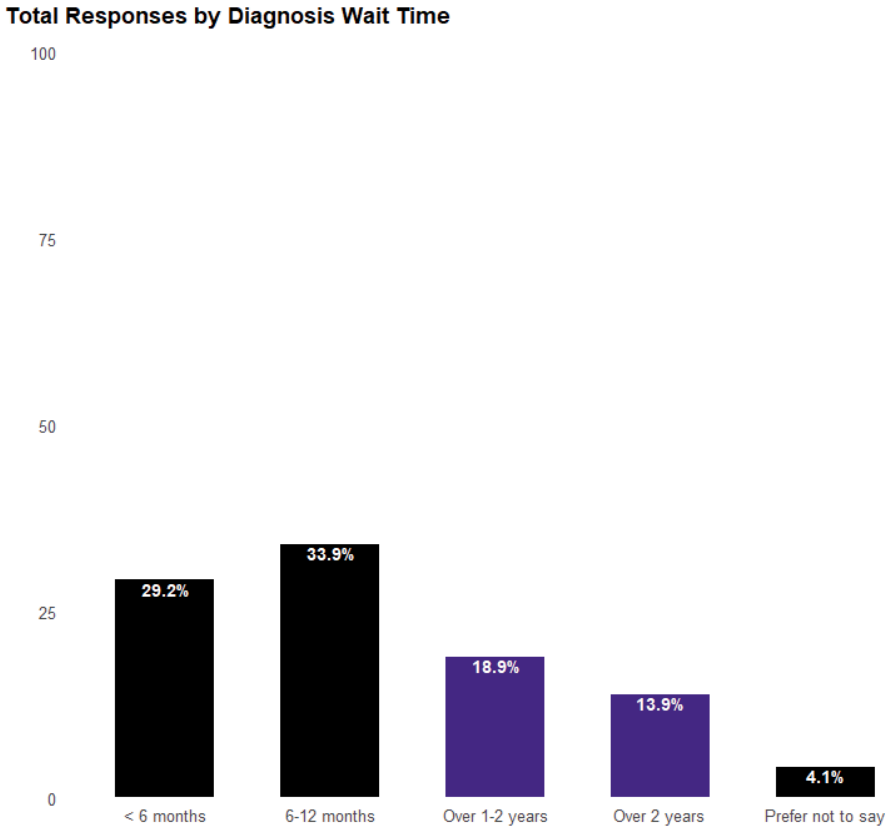
When stratified by ministry region, it was found that:

- The distribution of diagnosis wait times differs across regions. Residents in the North region experienced statistically significantly longer waits for autism diagnosis.
- In comparison, there were no other statistically significant regional differences.

This aligns with anecdotal evidence being collected by the OAC. One of Northern families' main points of advocacy has consistently been the wait time for autism diagnosis, due to fewer available specialists and capacity issues at OAP diagnostic Hubs.

It is the hope of the OAC that the province begins to invest meaningfully in attracting new specialists to the province, instead of creating new pathways to the same resource-deficient programs.

FIGURE 6: Approximately one-third of autistic people represented in this survey waited over 1 year for an autism diagnosis



RESULTS

DIAGNOSIS

At what age was the autism diagnosis received?

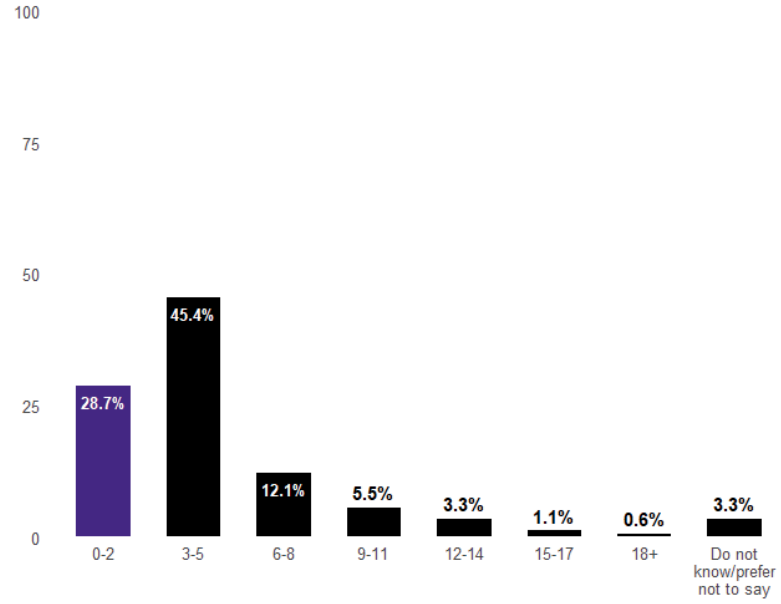
Most families reported that autism was identified in the preschool years, with nearly half receiving a diagnosis between ages 3 and 5. Another quarter reported receiving a diagnosis before age 3, while smaller numbers received diagnoses in middle childhood (ages 6–8) or adolescence. A very small proportion were diagnosed in adulthood. Based on data obtained through a Freedom of Information (FOI) request, as of August 6, 2025, there are 84,405 children and youth registered with the Ontario Autism Program (OAP) (See appendix B). Because registration requires a formal ASD diagnosis, this figure provides a credible minimum estimate of autism prevalence in Ontario. When compared to the 2.7 million children and youth identified in the 2021 Statistics Canada Census (3), this represents approximately 3.2%, or 1 in 32 children and youth, a number that exceeds the 1 in 50 figure reported in the 2019 Canadian Health Survey on Children and Youth (CHSCY) (4) and still likely underestimates true prevalence, as it excludes those awaiting or unable to obtain a diagnosis.

The presence of later and even adult diagnoses underscores that early identification is not yet a reality for everyone. In open-ended responses, many families described waiting years for assessments or travelling long distances to find a qualified professional. These delays have lasting impacts, particularly when early supports are unavailable during critical developmental windows. While these data reflect some progress toward earlier identification, they also highlight persistent inequities that delay access to diagnosis and early intervention.

Statistical analysis revealed significant regional differences in the age at which children were diagnosed. Children in Toronto were more likely to receive an early diagnosis (ages 0–5) and less likely to be diagnosed during middle childhood (ages 6–11), while northern regions showed a trend toward fewer early diagnoses, suggesting disparities in access to timely assessment and diagnostic services across the province.

FIGURE 7: Less than one-third of the autistic people represented in this survey received an autism diagnosis before the age of 3

Total Responses by Age at Diagnosis



ESTIMATED ASD PREVALENCE IN ONTARIO, 2025

1:32

RESULTS

DIAGNOSIS

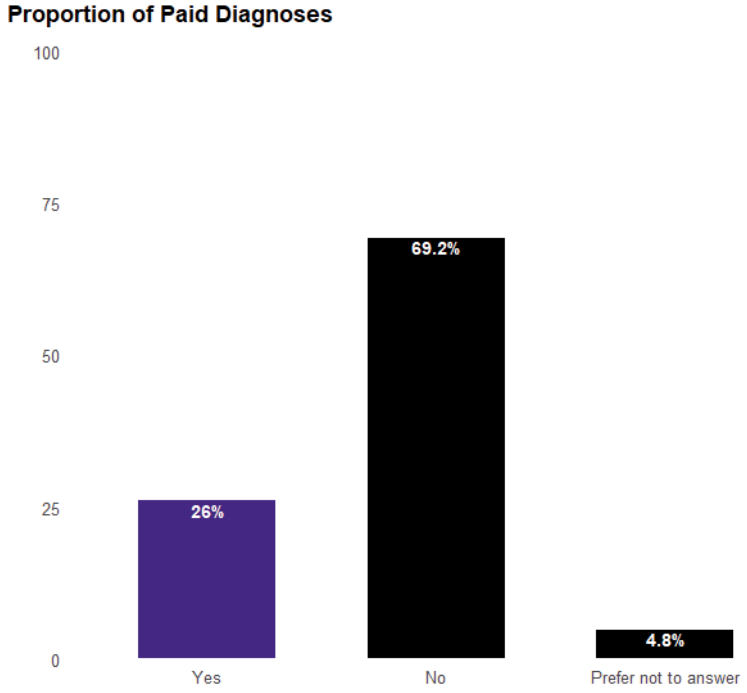
Did you have to pay out of pocket for this diagnosis?

This question asked respondents whether they paid out of pocket for their own or their child/youth's autism diagnosis. It was not time-specific; rather, it was intended to gauge the community's overall experiences with accessing autism diagnosis.

Just over a quarter of respondents (26%) reported that they paid out of pocket for their own or their child's autism diagnosis, while the majority (69%) were able to access a publicly funded assessment. Although most families did not incur direct costs, the fact that one in four did reflects ongoing inequities in access to timely diagnostic services. Many families continue to face long waitlists in the public system and turn to private providers to avoid years-long delays. This creates a two-tier system where families with financial means can move forward with early intervention, while others remain stalled, waiting for access that should be guaranteed. These findings reinforce the need for timely, equitable, and publicly funded diagnostic pathways so that early identification, a key determinant of better long-term outcomes, is not dependent on a family's ability to pay.

Families' experiences with paying out of pocket for an autism diagnosis were not the same across Ontario. About one in three families in the East (32%) and Central (29%) regions reported paying, compared with about one in four in Toronto (24%), about one in five in the North (21%), and fewer than one in five in the West (18%). The differences between regions were big enough to be meaningful, and the analysis showed that families in the West were much less likely to report having paid out of pocket than families in Central Ontario. In the East, North, and Toronto, families were about as likely to report having paid out of pocket as in Central, with no clear differences.

FIGURE 8: For those with an autism diagnosis, more than one-quarter were paid for out of pocket



RESULTS
DIAGNOSIS

Who did the diagnosis/assessment? (choose all that apply)

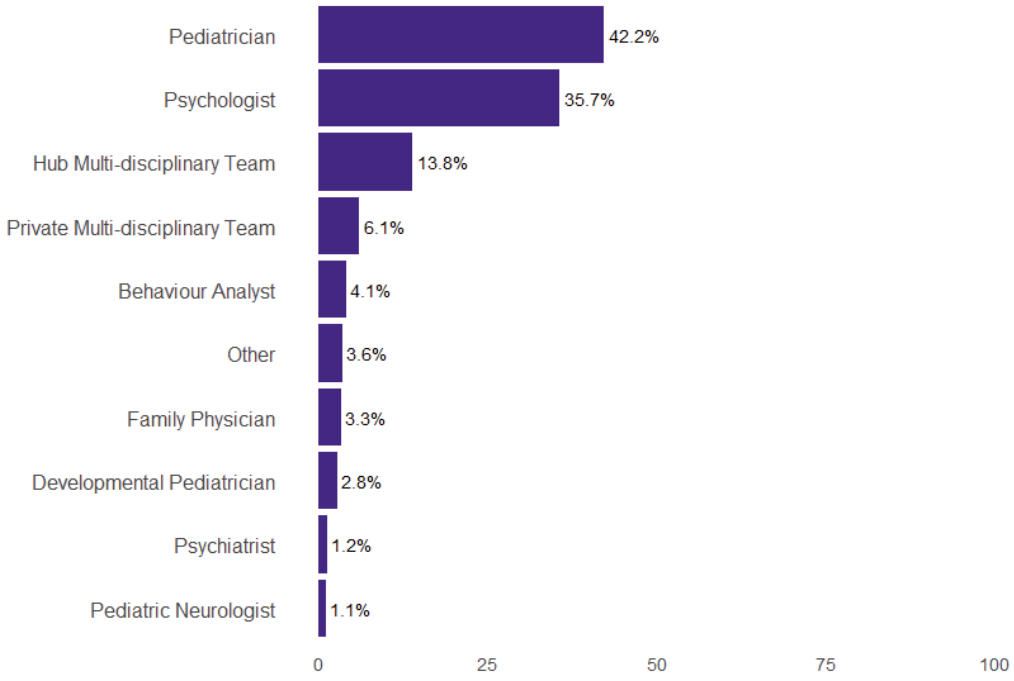
This question asked those respondents who had a diagnosis, which professionals were involved in their or their child or youth's autism diagnosis. Respondents could select all options that applied to their circumstances.

The majority of respondents reported that their or their child/youth's autism diagnosis included a pediatrician (42%) or psychologist (36%), indicating that these providers are the primary points of access for autism assessment. Provincial hub multi-disciplinary teams were used by 14% of respondents, while private multi-disciplinary teams accounted for 6%. Other professionals, including registered behaviour analysts, family physicians, developmental pediatricians, psychiatrists, and pediatric neurologists, were less frequently involved (each under 5%).

These results highlight that the use of publicly funded hub teams remains limited, reflecting that demand far exceeds current capacity. This underscores the need for the Ministry of Children, Community and Social Services (MCCSS) to provide long-term, consistent funding so hub teams can build capacity and ensure families across different regions have equitable access to timely, comprehensive autism assessments.

Note: the "other" category did include genetic specialists, allied health care, named providers, and notably, several families who reported going out of province, or country, to seek an autism diagnosis.

FIGURE 9: Pediatricians and Psychologists were reported most frequently by respondents as participating in their own or their child or youth's autism diagnosis (choose all that apply)



RESULTS

OAP ACCESS

Is the person this survey is about REGISTERED with the Ontario Autism Program?

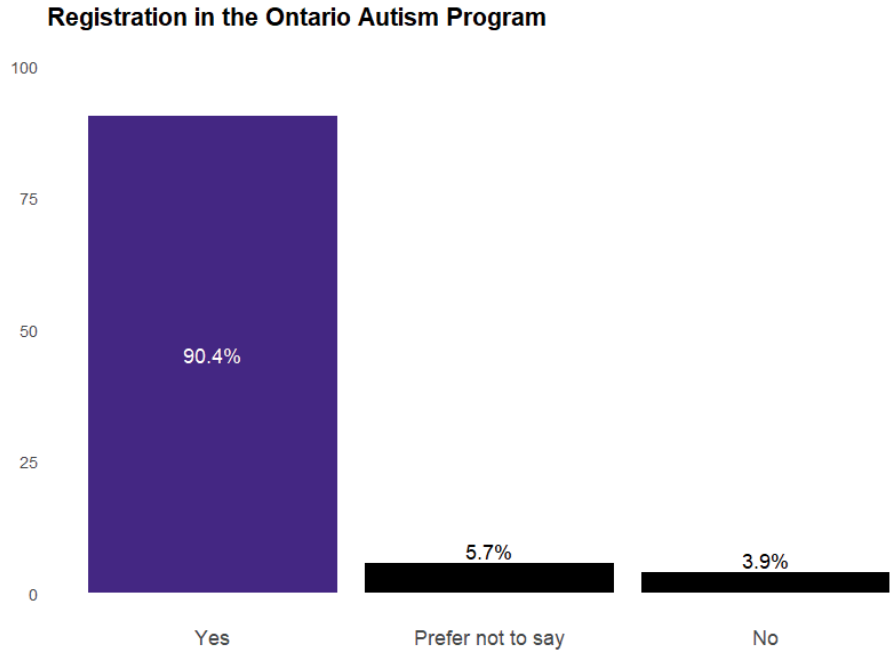
Those who indicated having an autism diagnosis were then asked if the person this survey is about is registered with the Ontario Autism Program (OAP).

A majority of respondents (n=906) reported that they are registered in the OAP at the time of the survey. Specifically, 90.4% indicated “Yes”, while 3.9% reported “No” and a small proportion (5.7%) preferred not to say. This finding suggests that while most families have managed to navigate the registration process, a notable minority remain outside of the program.

Given the OAP’s role as the gateway to autism services in Ontario, this gap is concerning (5). Families who are not registered reported facing barriers to accessing supports, delays in receiving services, or confusion about eligibility. Ensuring that all eligible families can register efficiently is essential. These results reinforce the need for greater outreach, clarity, and support in the registration process, as well as ongoing monitoring by the Ministry of Children, Community and Social Services (MCCSS) to ensure families are not left behind.

Across Ontario, the majority of children and youth who are eligible are registered in the OAP, with overall registration rates exceeding 92% in every region. Registration is highest in the East and lowest in the North. Statistical testing indicates a small overall difference between regions; this suggests that while registration is broadly high across the province, Northern communities may face slightly lower registration rates, highlighting the importance of ongoing attention to ensure equitable access to the OAP in all regions.

FIGURE 10: The majority of children/youth (0-17) represented in the survey, with an autism diagnosis, are registered for the Ontario Autism Program



RESULTS
OAP ACCESS

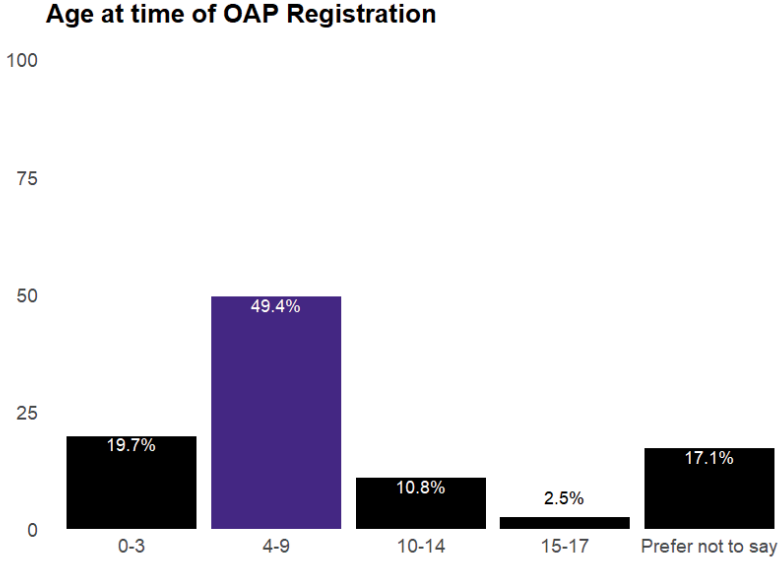
What was their age at the time of OAP registration?

Respondents who indicated “yes” to being registered to the Ontario Autism Program (OAP) were subsequently asked at what age registration occurred. Responses were categorized into the age ranges used for allocating core clinical services (CCS) funding, the most important component of the OAP, which provides consistent access to clinical services such as speech therapy, occupational therapy, behavioural therapy, and mental health supports (5). Using these age ranges allows the analysis to align with program guidelines and funding structures, highlighting how service access and wait times correspond to the stages at which children are eligible for supports under the OAP.

In this cohort, nearly half of children and youth (approximately 50%) were registered to the OAP between the ages of 4 and 9. The youngest group, ages 0 - 3, accounted for about 20% of registrations, while ages 10 - 14 represented roughly 11%, and the oldest group, 15 - 17, made up only 2.5% of the cohort. Additionally, 17% of respondents selected “Prefer not to say.” Given that the wait time between OAP registration and access to CCS funding now exceeds five years, the majority of children, those registered at age 4 and older, are only beginning to access these critical services around age 9 or later. This means many children are already approaching the upper age limits of the highest funding category or are aging out of them entirely at the time of program access. This underscores the negative impact of long wait times on service access and highlights that early intervention is not occurring as intended (6).

Looking at the proportions of registrations by age group within each region, the majority of children and youth are registered between ages 4–9 across all regions, typically making up around 58–67% of registrations, followed by ages 0–3 (roughly 17–28%), 10–14 (about 12–14%), and 15–17 (only 2–4%). Toronto and East show slightly higher early registrations, while North is slightly lower. This pattern is consistent with the age of diagnosis, where there was a slight trend toward older diagnoses in the North. It is therefore understandable that this would translate to older ages of registration in that region.

FIGURE 11: Half of the children/youth represented in the survey, with an autism diagnosis, were registered for the Ontario Autism Program between the ages of 4-9



RESULTS
OAP ACCESS

What is the reason for the timing of this OAP registration? (choose all that apply)

Respondents who indicated “no” to being registered to the OAP (but “yes” to having an autism diagnosis) were subsequently asked what might be the reason for the delay in registration. Respondents were invited to choose all that applied to them or use an open-ended option to describe their experience more accurately. A thematic approach was taken to interpreting this question, as the open-ended response option was used most frequently by respondents.

Barriers mentioned most frequently included:

- The child/youth aging out of the program before registration was available
- Not knowing what the Ontario Autism Program is or what it includes
- Not having access to, or being unaware of, any services to purchase in their area
- Needing help with registration and not knowing where to access that help
- Giving up trying to register due to wait times for core clinical services
- The process being too complicated and time-intensive

These barriers to registration highlight persistent gaps in awareness, access, and support. Of particular concern is the significant knowledge gap between ministry policy and the families who need it most, with many respondents reporting a lack of understanding about the OAP, its services, or how to access them. Limited or no availability of purchasable services in some areas further compounds the problem. Many families also described giving up due to long wait times for core clinical services, and characterized the registration process as overly complex and time-intensive; in fact, some of these families indicated making plans to leave the province to secure services due to the uncertainty and waitlists.

Collectively, these responses highlight an urgent need for clearer information about the OAP, more accessible support for navigating the registration process, and expanded service availability across regions. A key recommendation is greater transparency from the ministry, enabling families to make informed decisions for their children. Addressing these barriers is essential to ensure equitable access to timely and appropriate supports for all autistic children and youth and their families, and to prevent delays that can have lasting impacts on development and wellbeing.

“Wait time of 5-7 years is insane. Had to move to another province for my child.”

“I don’t know if the program covers what we need... I was discouraged.”

I was discouraged. I wonder what’s the point because wait times are so long.”

RESULTS

ENTRY TO SCHOOL

What is Entry to School:

The Ontario Autism Program's Entry to School (ETS) pillar program supports children entering kindergarten or Grade 1 for the first time (7). The program begins with a six-month, group-based phase focused on developing school-readiness skills such as communication, play, social interaction, self-help routines, behaviour regulation, and early learning skills. Afterward, families are supposed to receive transition support as their child starts school, including consultation and collaboration with educators to promote consistency and success. The program is free for eligible children registered in the OAP and is intended to ease the transition to school by building foundational skills and ensuring smoother adjustment during the early months of entry.

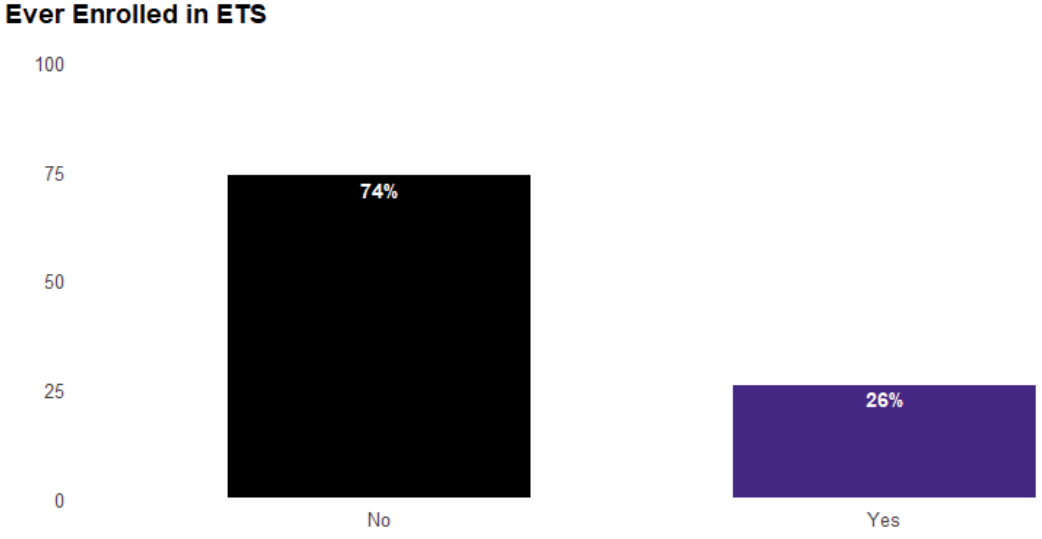
Have you EVER accessed the Entry To School Program?

Respondents who indicated "yes" to being registered to the OAP were subsequently asked if they had ever accessed the ETS Pillar Program.

The survey results show that only 26% of children and youth registered in the Ontario Autism Program (OAP) had ever accessed the ETS program, while the majority (74%) had not. This finding underscores the limited reach of ETS within the OAP population. Given that ETS is designed to support one of the most critical and challenging transitions for autistic children, starting school, this gap raises serious concerns. It suggests that a large proportion of children are either not eligible or face barriers to entry, meaning that many families may be missing out on a program intended to provide foundational school readiness support.

When stratified by ministry region, there is an observed trend where children in Toronto and West Ontario are somewhat more likely to have ever accessed ETS compared to the Central and East regions. Northern regions fall in between. This pattern may suggest that urban areas have better access to ETS services, whereas more rural or centralized regions may face logistical barriers.

FIGURE 12: A quarter of the children represented in the survey, registered for the OAP, have ever accessed the Entry to School (ETS) pillar program



RESULTS
ENTRY TO SCHOOL

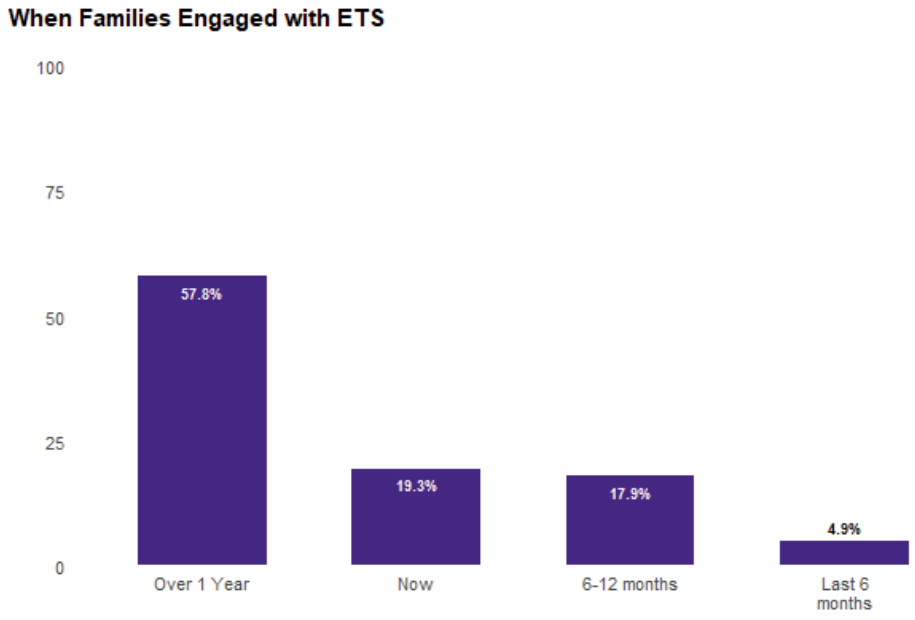
When did you access the Entry to School Program?

Those respondents who indicated ever accessing the Entry to School Pillar Program (ETS) were then asked when they had accessed it.

Among these families, engagement timing varied: 19.3% reported “Now,” 4.9% in the “Last 6 months,” 17.9% in “6–12 months,” and the majority (57.8%) over a year ago.

Even among the relatively small group of children who have ever accessed the ETS program, only a minority were actively participating at the time of the survey. Overall, just about 4.2% (or approximately 1:24) of the total OAP-registered children were actively engaged in ETS at the time of the survey, underscoring the limited enrollment and ongoing participation. Most children accessed the program more than a year ago, indicating the time-limited nature of the program. This low ongoing participation reflects the program’s restricted age eligibility, as ETS is available only to children approaching school age, meaning only a narrow segment of OAP-registered children can access this pillar at any given time. Together, these findings highlight that ETS currently reaches only a small fraction of the OAP-registered population, with the majority of children not actively accessing the program at the time of the survey.

FIGURE 13: Fewer than a quarter of children who have ever accessed the Entry To School pillar program were actively in the program at the time of the survey



RESULTS
ENTRY TO SCHOOL

How long did you wait to access the Entry to School Program after receiving the invitation?

Those respondents who indicated ever accessing the Entry to School Pillar Program (ETS) were then asked how long they waited to access the program after receiving the invitation.

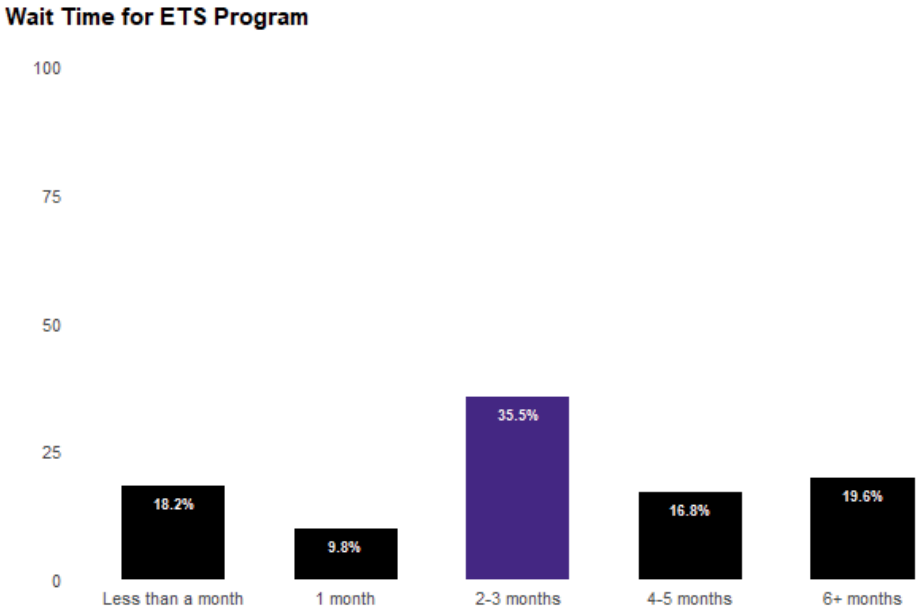
The survey results show that wait times for the ETS program vary considerably among families. Among the children who accessed the program, 35.5% waited 2–3 months, making it the most common wait time. Shorter waits were less frequent: 18.2% of children waited less than a month, and 9.8% waited 1 month. Longer waits were also substantial, with 16.8% waiting 4–5 months and 19.6% waiting 6 months or more. While some children can access the program quickly, a large fraction experience moderate to long delays, highlighting challenges in timely engagement with ETS. This pattern of wait times is partly a feature of the program's design, as it is offered regionally.

Did you complete the entire Entry to School Program?

ETS families were also asked if their child had completed the program.

While the majority of children who accessed the ETS program completed it, a notable proportion did not. Specifically, 18.7% of children did not finish the program, meaning that almost one in five children fail to complete the full ETS sequence. This highlights a significant gap in program engagement and suggests that even after gaining access, a substantial number of children are unable to benefit from the entire program. This aligns with reports the OAC has been receiving from families about local program changes, added limitations and barriers to being allowed to participate in the program.

FIGURE 14: More than a third of children who have ever accessed the Entry To School pillar program waited 2-3 months to access it



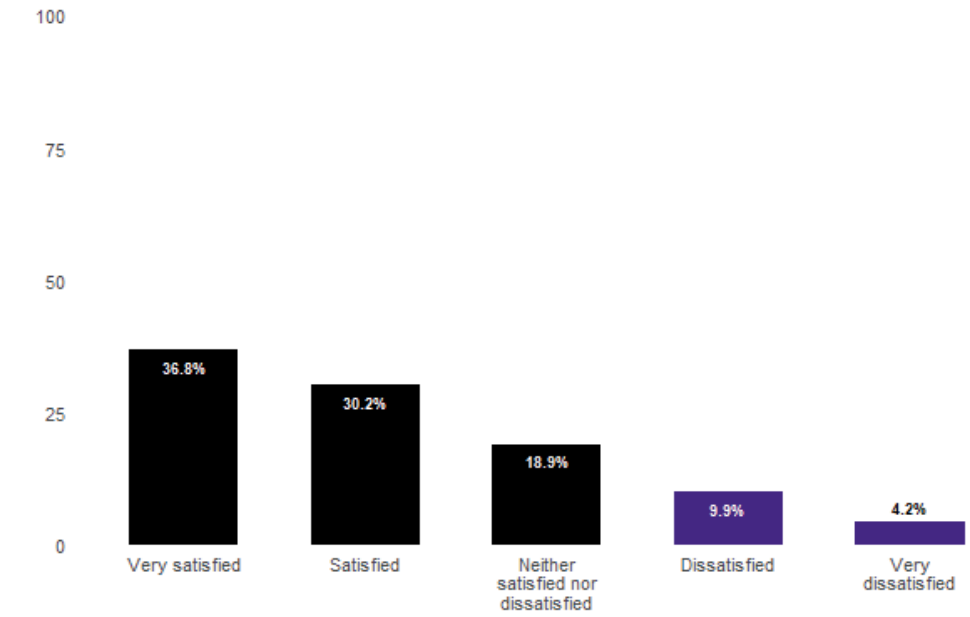
RESULTS
ENTRY TO SCHOOL

Please indicate your satisfaction with the Entry to School Program:

Those respondents who indicated ever accessing the Entry to School Pillar Program (ETS) were then asked about their satisfaction with the program.

The survey results show that most families were satisfied with the Entry-to-School (ETS) program: 36.8% reported being “Very satisfied” and 30.2% “Satisfied”, together accounting for 67% of respondents. A smaller portion was neutral (18.9%) regarding their satisfaction. However, a notable minority experienced dissatisfaction, with 9.9% “Dissatisfied” and 4.3% “Very dissatisfied”, meaning that almost 15% of families were not satisfied, on some level, with the program. These findings indicate that while ETS meets the needs of the majority, a meaningful subset of families face challenges or unmet expectations, which may reflect program design, accessibility, or other barriers.

FIGURE 15: Almost two-thirds of families who have ever accessed the Entry To School pillar program were satisfied with the program



RESULTS
ENTRY TO SCHOOL

Please indicate your satisfaction with the Entry to School Program (ETS):

Families who answered the ETS satisfaction question were then asked to indicate why they chose that level of satisfaction.

Families' experiences with the Entry to School (ETS) Program were deeply mixed, revealing both significant benefits and major barriers. Many parents praised the program for helping their children learn essential school-readiness skills such as following routines, toileting, socializing, and managing transitions, often crediting dedicated and compassionate staff for their children's growth. Several described it as a "game changer" that eased anxiety and built confidence for both children and families. However, recurring challenges emerged: half-day schedules made participation nearly impossible for working parents; transportation barriers were significant, especially in regions without local programs; and communication gaps between staff and families limited collaboration. Some participants felt the program lacked individualization, while others said it didn't adequately bridge to the child's actual school experience. Families also expressed frustration with limited follow-up support after completion, describing a "service gap" between ETS and further OAP interventions. Overall, while the ETS program clearly helps many children prepare for school, its structure and accessibility remain misaligned with the realities and diverse needs of Ontario families.

RESULTS
URGENT RESPONSE SERVICES

What are Urgent Response Services (URS)?

Urgent Response Services (URS) were introduced within the Ontario Autism Program to provide short-term, immediate support for children and youth experiencing a specific, urgent need (8). These services were designed to stabilize situations, prevent crises, and reduce risks of harm to the child, others, or property. To qualify, families must demonstrate that one or more high-risk factors have emerged or worsened in the past 14 days. The high-risk factors which are eligible include:

- **aggression**
- **property destruction**
- **violent thinking**
- **fire setting**
- **harm to animals**
- **risk of exploitation**
- **self-injurious behaviour**
- **suicidal thoughts or behaviour**
- **inappropriate sexual behaviour**
- **flight risk**

If deemed eligible through the intake process, families can access up to 12 weeks of time-limited supports, which may include consultation with clinicians, respite, service navigation, or direct behaviour support. Importantly, URS does not provide funding but instead delivers a tightly scoped package of short-term interventions, often requiring collaboration between professionals, families, and support networks.

In practice, however, URS falls short of meeting the ongoing needs of many families. The strict eligibility requirements mean that only a fraction of families qualify, and even then, the supports are capped at 12 weeks, far less than what most children and youth with complex needs require to achieve stability. Services can also vary significantly by region, and families frequently describe long waits, confusing processes, or supports that do not align with the realities they face. Because URS is positioned as the system's "safety net," these limitations leave many families with urgent needs unsupported, and they underscore the inadequacy of relying on short-term crisis intervention as a substitute for a comprehensive, sustainable autism program.

RESULTS
URGENT RESPONSE SERVICES

Have you ever accessed the Urgent Response Services Program (URS)?

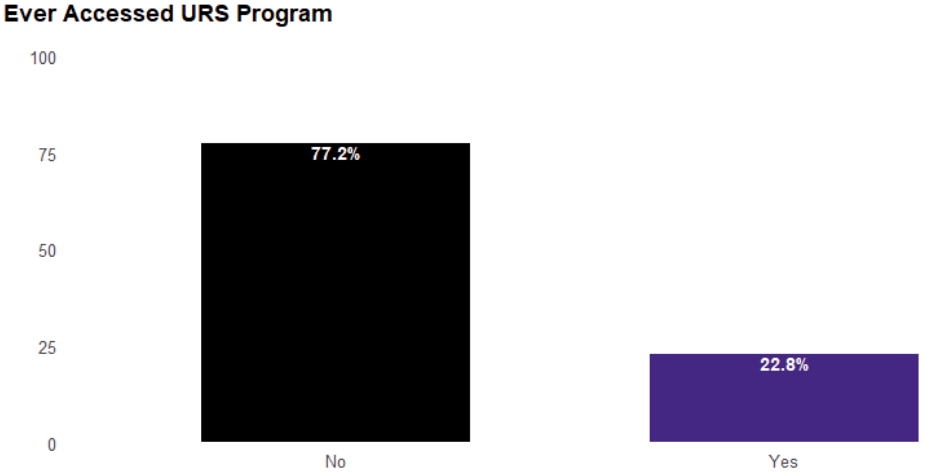
Those respondents who indicated being registered to the OAP were asked if they had ever accessed the Urgent Response Services pillar program.

The data indicate that approximately 23% of children and youth registered to the OAP have accessed the Urgent Response Services (URS), while 77% have not. Given that URS is a time-limited, short-term intervention designed to address 10 very specific, immediate and high-risk needs, this low uptake is not unexpected. Eligibility for URS requires a recent escalation of such behaviours, and services are typically provided for up to 12 weeks following a standardized intake process. Services are also dependent on what is available locally.

While the limited uptake reflects the program's targeted criteria, the fact that the majority of children have not accessed URS also highlights that many are likely navigating significant needs without timely or intensive support. The results suggest that children and youth may not be receiving support until they are in crisis, emphasizing the importance of earlier, more accessible, and preventative supports to reduce the risk of urgent situations.

Access to URS remains very limited across Ontario. Only 17-30% of children and youth across the different regions had ever received URS, reflecting the program's narrow eligibility and capacity. There is no statistically significant difference between regions, highlighting that the limited reach of this program is a province-wide issue, not isolated to any single area. These results underscore that children and youth with urgent or complex needs are consistently underserved, regardless of where they live, leaving families without critical supports at key moments.

FIGURE 16: Approximately one-quarter of families have ever accessed the Urgent Response Services pillar program



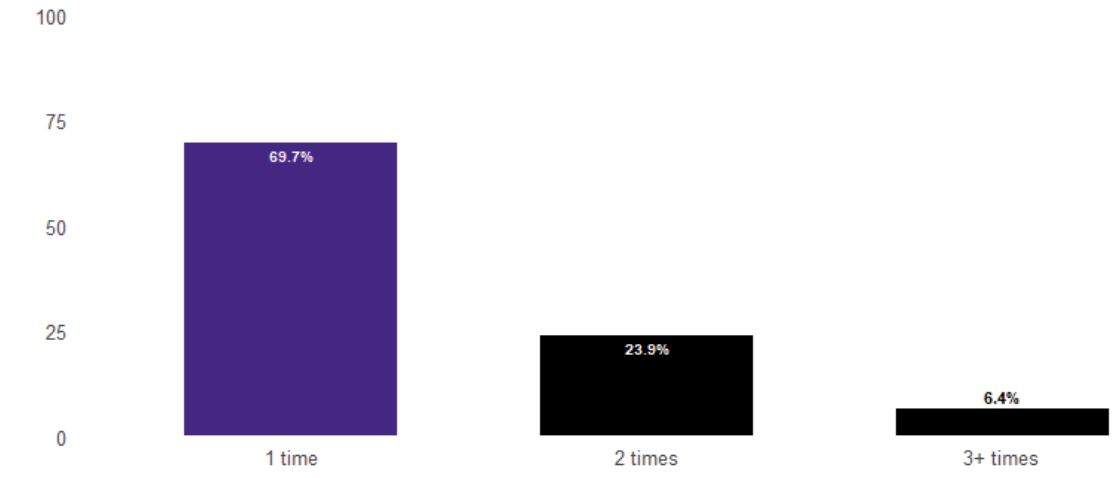
RESULTS
URGENT RESPONSE SERVICES

How many times have you accessed the Urgent Response Services program (separate signed contracts)?

Those respondents who indicated accessing Urgent Response Services (URS) were then asked how many times they had accessed the program (separate signed contracts).

Nearly 70% of families were able to access the program only once, with very few accessing it multiple times. The limited duration of URS often does not provide sufficient time to meaningfully resolve issues at the level identified in the program, creating significant ethical and practical concerns. Community feedback highlights that in some regions, the severity of children's needs exceeds the program's eligibility criteria, leaving the most urgent cases without support. These trends and capacity constraints across the province underscore that the program's reach is insufficient and that systemic gaps persist, regardless of geographic region.

FIGURE 17: The majority of families who have accessed URS have done so once



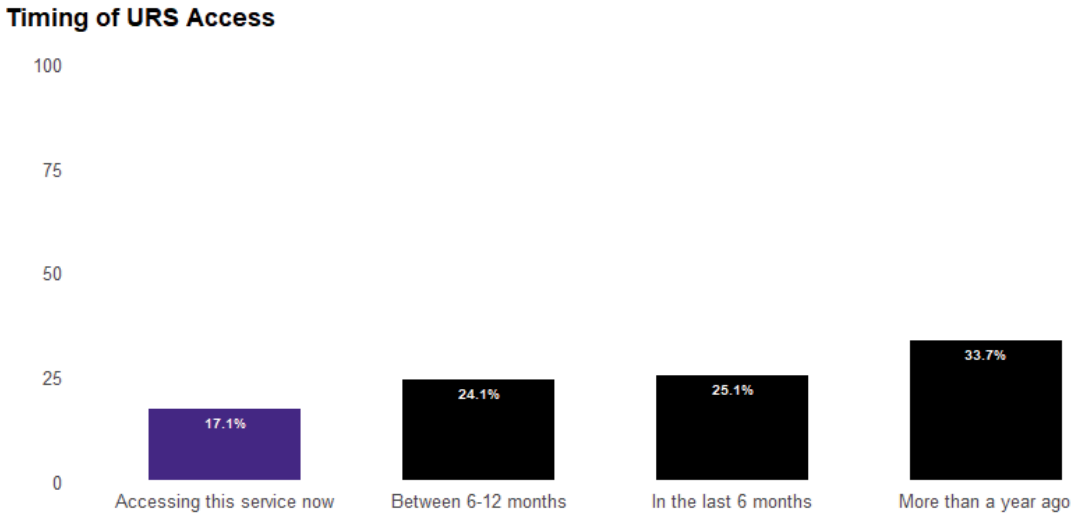
RESULTS
URGENT RESPONSE SERVICES

When did you last access Urgent Response Services?

Families who had indicated ever accessing the URS pillar program were then asked when they had last accessed it.

The data on timing of URS access shows that only 17% of children and youth were actively accessing the URS at the time of the survey. Most families accessed the service in the past, with 25% in the last 6 months, 24% between 6 to 12 months ago, and 34% more than a year ago. Because URS is designed as a one-time, short-term intervention of up to 12 weeks per child, this pattern reflects the program's strict limits on usage rather than repeated access (8). While a few families were able to access URS more than once, these cases are exceptional. Taken together, these findings suggest that many urgent needs may go unaddressed or are delayed, particularly when crises exceed the program's limited duration or intensity, highlighting systemic gaps in timely support for children and youth across the province.

FIGURE 18: The majority of families who have accessed URS have done so over a year ago



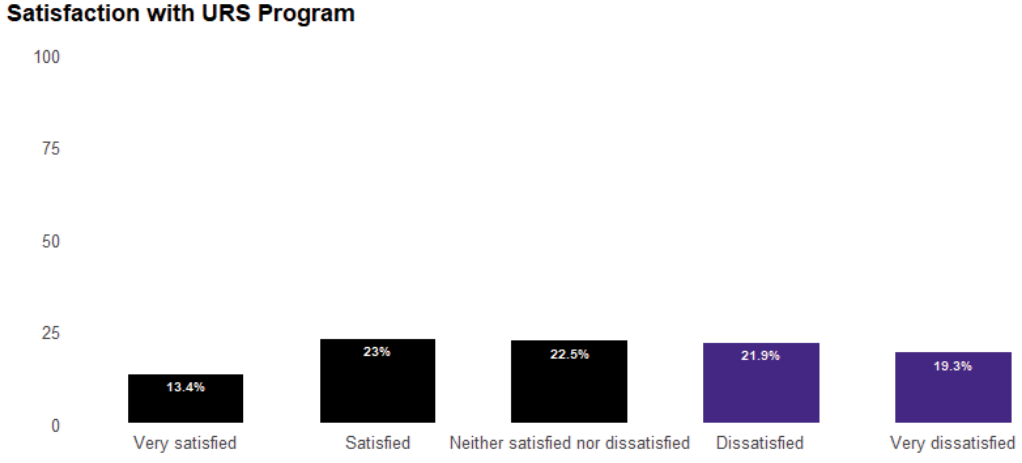
RESULTS
URGENT RESPONSE SERVICES

Please indicate your satisfaction with the Urgent Response Services Program

Families who had indicated ever accessing the URS pillar program were then asked about their satisfaction with the program.

Families' experiences with the URS program are clearly mixed. While some report satisfaction, 41.2% of respondents indicated they were dissatisfied or very dissatisfied, and only 13% reported being very satisfied. The remainder of the families were neutral. This distribution underscores that, for a significant portion of children and youth, the program is not meeting needs effectively. Given the program's design, limited to one crisis per child and lasting a maximum of 12 weeks, with capacity challenges in some regions, it is clear that the program's reach and impact are constrained. The data suggest that these limitations affect families across the province, highlighting the ongoing need for support that adequately matches the complexity and urgency of children's needs.

FIGURE 19: 41.2% of families who have accessed the Urgent Response Services pillar program were dissatisfied with the service



RESULTS
URGENT RESPONSE SERVICES

Please indicate your satisfaction with the Urgent Response Services Program

Families were then offered space in the form of an open-ended question to describe why they had chosen a particular level of satisfaction with the URS pillar program.

Families accessing the Urgent Response Services (URS) pillar program consistently report that while the program offers some immediate support, it is too limited in scope and duration to adequately address complex behavioural and mental health needs. The program's 12-week timeframe, focus on parent-led interventions, and restriction to addressing only one behaviour at a time mean that many families experience a "band-aid" effect: temporary relief without sustainable outcomes. Delays in intake, regional inequities in access, and insufficient coordination of services exacerbate stress for families already facing crises. While some families appreciated the professionalism and empathy of individual providers and the respite support offered, overall, the program often fails to meet urgent needs, leaving families frustrated, burned out, and without long-term solutions.

Families described multiple barriers that prevented them from accessing Urgent Response Services when support was most needed.

Eligibility and Criteria Barriers
Many families were denied access because their child did not meet strict URS criteria. Behaviours were often deemed "not severe enough," particularly if the child was not suicidal, violent, or self-harming. Others were excluded due to age restrictions, because behaviours occurred at school rather than at home, or because their situation was considered "not urgent enough." Families perceived URS as a program reserved only for extreme crises, making it inaccessible for early intervention or moderate behavioural concerns.

Lack of Awareness and Regional Availability
A significant number of respondents reported that they were unaware URS existed, unsure how to access it, or unclear about what the service could provide. Some noted that URS is not available in their region, effectively making access impossible even when they met eligibility criteria. Others hesitated to reach out, uncertain whether their situation qualified.

Timing and Waitlist Challenges
Families frequently reported long waits for intake or services, sometimes several months. In some cases, the service was unavailable when needed due to staff shortages or incomplete regional rollout. By the time support was offered, the crisis had often passed or the child's needs had changed.

Perceived Limitations of Support
Even among those who accessed URS, many felt the support did not meet their child's needs, particularly for sensory-based or non-ABA approaches. Some feared that URS interventions could worsen behaviours or fail to address underlying issues. Others described the service as too short-term, insufficient, or overly focused on parent coaching rather than direct intervention.

Alternative Supports and Personal Barriers
In the absence of accessible URS, families turned to hospital crisis teams, dual-diagnosis programs, psychiatrists, or existing caseworkers with varying levels of success. Many also cited exhaustion, competing appointments, distance, or financial strain as additional barriers to seeking or sustaining support.

Families who did not access URS reported eligibility restrictions, lack of awareness, regional unavailability, long wait times, and concerns about effectiveness as the main barriers. Strict criteria often excluded children in genuine need, particularly for moderate crises, school-based behaviours, or sensory issues. Logistical and personal challenges, such as exhaustion, unclear processes, and alternative supports, also limited uptake. Overall, URS is often seen as inaccessible, narrowly targeted, and reactive rather than preventative.

RESULTS
FOUNDATIONAL FAMILY SERVICES

What are Foundational Family Services?

Foundational Family Services (FFS) are described as flexible, evidence-informed supports available at no cost to all families, meant to empower caregivers, ease transitions, and reduce stress throughout a child's developmental journey (9). The promise is that families can access timely workshops, mentoring, consultations, and coaching whenever they need them, creating a responsive and accessible layer of support.

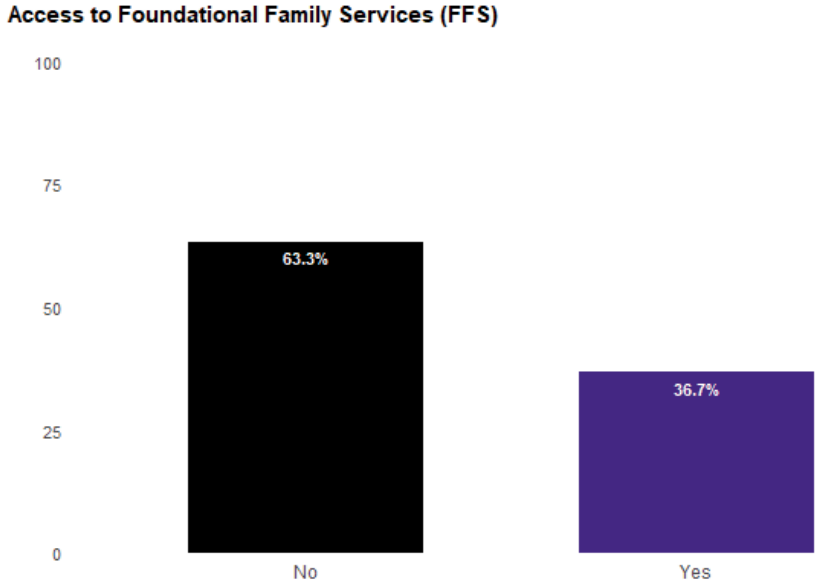
However, as the data below illustrates, the reality does not always match the description. While the framework of FFS may look impressive, families consistently report barriers such as limited availability, uneven access across regions, and services that do not meet the intensity or timeliness of their child's needs. This disconnect raises the question of whether FFS are more of a theoretical safety net than a practical one, something that looks good in policy documents but too often fails to deliver meaningful support in practice

Have you ever accessed a Foundational Family Services pillar program?

Those respondents who indicated being registered to the OAP were asked if they had ever accessed the Foundational Family Services pillar programs.

Just over one-third of families (36.7%) reported being able to access Foundational Family Services (FFS), while nearly two-thirds (63.3%) said they had not. Given that FFS is intended to be the broadest and most universally available component of the Ontario Autism Program, these results are concerning. A program designed to be widely accessible clearly does not reach the majority of families. This raises serious questions about how the program is being delivered in practice and whether families are truly able to benefit from the support that the government claims is available to all.

FIGURE 20: Approximately one-third of the children represented in the survey, registered for the OAP, have ever accessed the Foundational Services Pillar Program



RESULTS
FOUNDATIONAL FAMILY SERVICES

Foundational Family Services Regionally:

Access to Foundational Family Services (FFS) is not uniform across Ontario. While roughly one in three families (37%) report ever having used FFS, the likelihood of accessing these supports differs sharply by region. Families in Central Ontario are the least likely to have accessed FFS, with only 25% reporting use, compared to 44% of families in both East and West regions. Families in Toronto and Northern Ontario fall in between these extremes.

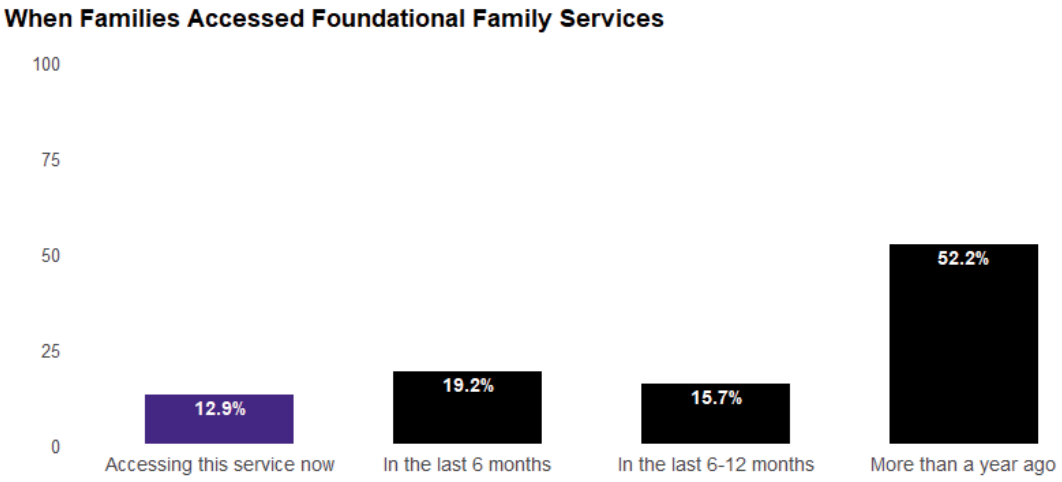
These differences are statistically significant; families in Central Ontario are significantly less likely to access FFS than those in East and West regions. This pattern points to a troubling inequity: children and youth's access to critical supports depends in part on where they live. Ensuring equitable access across all regions is essential so that every family, regardless of location, can receive the support they need to prevent crises and promote well-being.

When did you last access a Foundational Services (FFS) Pillar Program?

Families who had indicated ever accessing the FSS pillar program were then asked when they had last accessed it.

The data show that just over half of respondents (52%) last accessed Foundational Family Services more than a year ago, suggesting that many families have not been able to maintain ongoing or recent access. Only about one in eight families (13%) are accessing services at the time of the survey, while another 19% did so in the past six months and 16% between six and twelve months ago. Taken together, this suggests that timely and sustained access is limited, with most reporting it has been quite some time since their last use.

FIGURE 21: The majority of families who have ever accessed Foundational Family Services (FFS) have done so over a year ago



RESULTS
FOUNDATIONAL FAMILY SERVICES

How many foundational services programs have you accessed?

Families who indicated accessing Foundational Family Services were then asked how many services they had accessed.

The majority of families reported accessing 1 to 2 foundational family services, with 63.6% falling in this category. A smaller proportion of families accessed 3 to 4 services (16%), and the numbers drop sharply for higher service use: 5 to 6 services (6.7%), 7 to 8 services (3.5%), and 9 to 10+ services (10.2%).

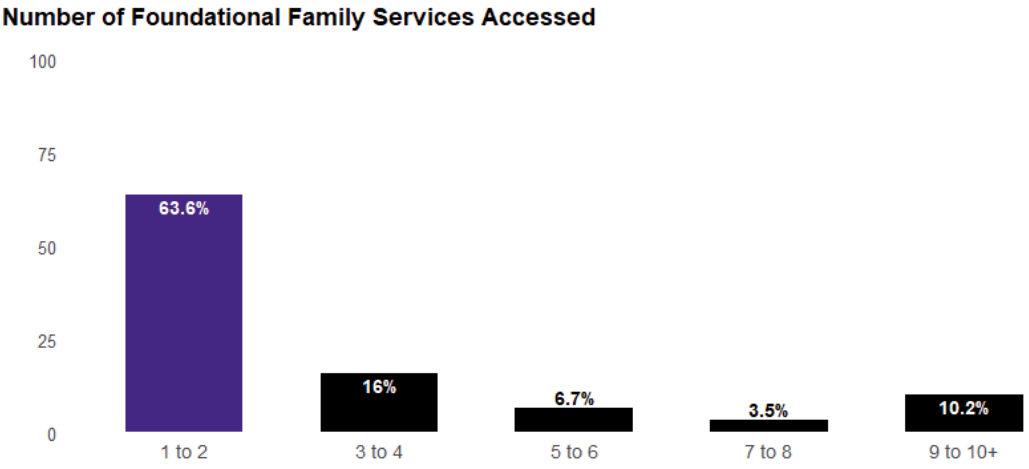
This pattern suggests that while most families engage with a minimal set of services, relatively few are accessing a broader range of supports. The steep drop-off after the 1–2 services category may indicate barriers to accessing multiple services, such as availability, eligibility criteria, or lack of awareness.

"By the time the therapist has established trust, the block is over and they need to start over months later."

"It's useful background information but not very impactful."

"I think they are somewhat helpful... but we are not able to discuss in depth my child's specific concerns and do not get tailored advice."

FIGURE 22: The majority of families who have accessed Foundational Family Services (FFS) accessed 1-2 programs



RESULTS
FOUNDATIONAL FAMILY SERVICES

Please indicate your overall satisfaction with Foundational Family Services Programs:

Families who had indicated ever accessing the Foundational Family Services (FFS) pillar program were asked about their satisfaction with the program.

Satisfaction with FFS shows a mixed picture. The largest share of respondents reported being satisfied (38.2%), followed by those who were neither satisfied nor dissatisfied (31.7%). Only 10.7% reported being very satisfied, while 13.9% were dissatisfied and 5.5% were very dissatisfied.

Taken together, just under half of respondents (48.9%) expressed some level of satisfaction, compared to 19.4% who expressed dissatisfaction. A significant portion, nearly one-third, fell in the neutral category, suggesting that many families may be experiencing services that are adequate but not meeting their full needs. This distribution indicates that while most families are not outright dissatisfied, high satisfaction remains relatively rare. The data highlights opportunities to strengthen the program so that more families move from “neutral” or “basic satisfaction” toward being genuinely very satisfied with the supports they receive through FFS.

Open response feedback from families reveals that while some found workshops and coaching useful for basic orientation after diagnosis, the vast majority reported that services are too generic, repetitive, and heavily reliant on parent-led strategies. Families consistently highlighted the lack of individualized, sustained, and child-focused supports, with virtual delivery, scheduling barriers, and short program blocks further limiting impact. While there were pockets of positive experiences, the overall picture points to FFS being inadequate to meet the complex and ongoing needs of autistic children and their families.

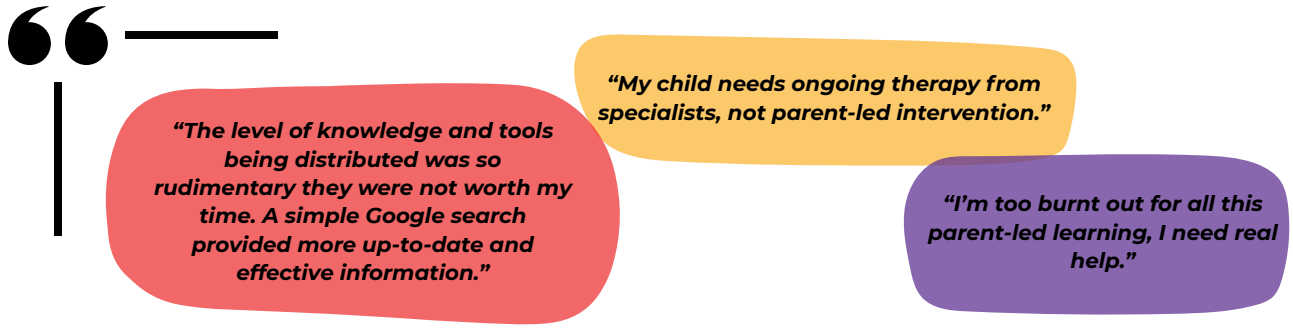
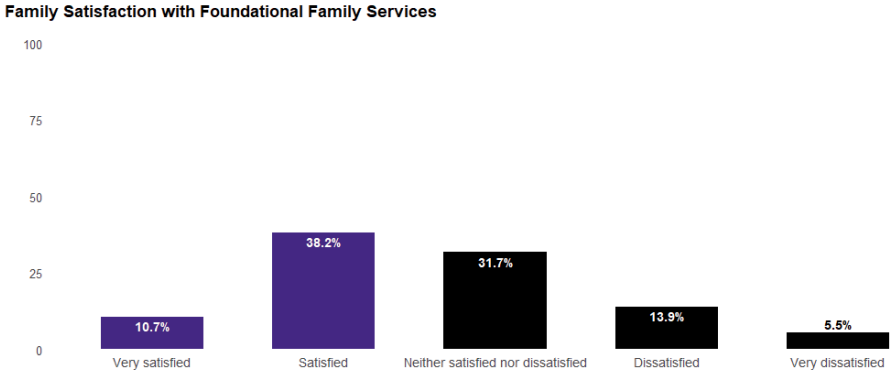


FIGURE 23: Approximately half of the families who have accessed the Foundational Family Services pillar program were satisfied with the service



RESULTS
FOUNDATIONAL FAMILY SERVICES

Why Families Did Not Access Foundational Services

Among families who did not access FFS (63.3% of those registered to the OAP), the most common reasons were lack of awareness (32%), lack of availability (17%), and perceived irrelevance (12%). The open-ended responses provide deeper insight into additional barriers and frustrations.

Key Themes:

1. Lack of Awareness or Clarity: Many families had never heard of FFS, were unsure what was offered, or did not realize workshops they had attended were part of the program.
2. Not the Right Kind of Support: Families repeatedly emphasized that FFS offers information sessions and parent coaching rather than the direct, individualized therapy their children need. Several noted the programming was too basic, too short, or not relevant to their child's profile.
3. Timing, Availability, and System Navigation: Some families reported FFS was not running when they needed it, or that scheduling conflicts and waitlists made access difficult.
4. Reliance on Parent-Led Models: Families expressed frustration that the services place too much responsibility back on caregivers, adding to burnout rather than alleviating it.
5. Prior Experience or Alternatives: A number of families explained that they already had training, had used similar programs in the past, or were accessing services privately while waiting for funding.

"The foundational services are not really relevant to my child. I don't need more short consults about what my child needs, then be on a waitlist for those needs."

"Caregiver burnout and my own mental health have prevented me from being able to join virtual workshops to help address my child's concerns myself at home."

"I don't really know what they are. I think they're webinars? Seems like more effort than actual help. I don't have time to attend webinars or sessions. I need direct help with behaviour through therapy."

RESULTS
CAREGIVER-MEDIATED EARLY YEARS PROGRAMS

What are Caregiver-Mediated Early Years Programs (CMEY)?

The CMEY pillar program is intended for young children (ages 12 to 48 months) who are registered with OAP. These programs are free of charge, up to six months in duration, and are designed to help families build skills for supporting their child's development (10).

Through CMEY, parents and caregivers learn therapeutic strategies and techniques from professionals that are tailored to their child's individual needs. Key developmental areas targeted include social interaction, play, communication, emotional regulation, and adaptive/self-help skills. The approach is play-based, child-led, and developmentally appropriate.

There are multiple evidence-based program models offered under CMEY, such as ESI/SCERTS, JASPER, Pivotal Response Treatment (PRT), Project ImPACT, Social ABCs, and the PLAY Project (10). These vary in format (group, one-on-one), mode (in person or virtual), and length (e.g. 6-week, 12-week, or 24-week sessions) depending on the provider (10).

Eligibility and Access

- Children must be registered with OAP and in the 12-48-month age range.
- Children who are already receiving OAP core clinical services or have an active behaviour plan are not eligible for CMEY simultaneously.
- Families who are eligible receive an invitation from AccessOAP. Once invited, they can choose among the providers offering CMEY, register directly with a provider, and begin services.

RESULTS
CAREGIVER-MEDIATED EARLY YEARS PROGRAMS

Have you ever accessed Caregiver-Mediated Early Years pillar programs?

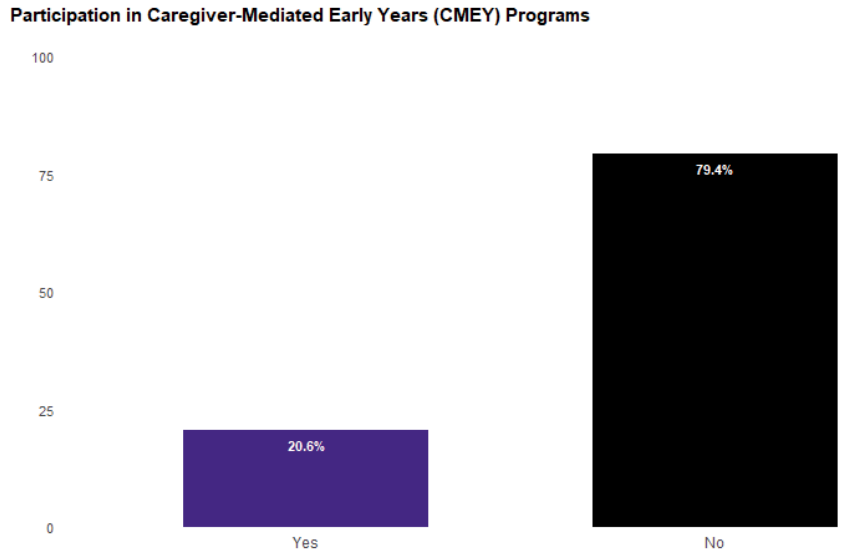
Those respondents who indicated being registered to the OAP were asked if they had ever accessed the Caregiver Mediated Early Years (CMEY) pillar programs.

Only one in five families (20.6%) reported having accessed CMEY pillar programs, while nearly four out of five (79.4%) indicated they had not. This highlights a very low rate of uptake for CMEY, suggesting that most families are either not eligible for (these programs have a very narrow age of eligibility) or not finding these services useful or accessible. The gap points to a need for clearer information, broader availability, and greater relevance to the needs of children and families.

CMEY Regionally:

Participation in caregiver-mediated early years programs remains relatively low across Ontario, with only about one in five families reporting that their child or youth had accessed these services. Rates of participation ranged from roughly 14% in the North to 25% in Toronto and the West, with Central and East regions falling in between. Confidence intervals around these estimates indicate some variability, but statistical testing shows no significant differences between regions. This suggests that, despite regional differences in service availability and population density, the overall access to caregiver-mediated early years programs is limited throughout the province.

FIGURE 24: Approximately one-third of the children represented in the survey, registered for the OAP, have ever accessed the Caregiver-Mediated Early Years pillar program



RESULTS
CAREGIVER-MEDIATED EARLY YEARS PROGRAMS

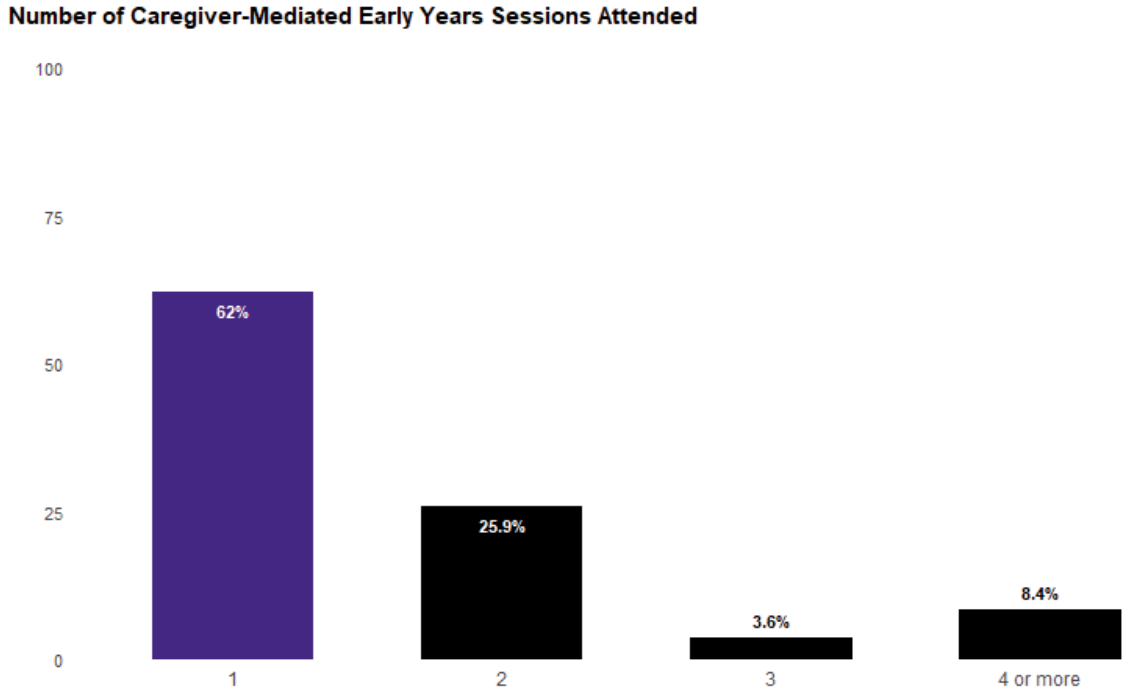
How many Caregiver-Mediated Early Years programs have you accessed?

Families who indicated accessing the Caregiver Mediated Early Years (CMEY) pillar program were asked how many programs they were able to access

The data show that most families who accessed CMEY pillar programs reported participating in one offering (62%). About one in four families (26%) reported attending two programs, while a much smaller proportion reported attending three (3.6%). Only 8.4% of families indicated attending four or more programs, even after combining categories to account for low reporting.

This pattern suggests that while the program reaches families initially, participation tends to drop off quickly. The relatively low numbers beyond two offerings may reflect barriers such as scheduling challenges, caregiver capacity, or a lack of perceived value in continuing multiple programs. It indicates that the program may not be meeting family needs in a sustained way, and points to the importance of understanding what prevents families from ongoing engagement.

FIGURE 25: The majority of families who have accessed Caregiver Mediated Early Years (CMEY) have accessed only 1 program



RESULTS
CAREGIVER-MEDIATED EARLY YEARS PROGRAMS

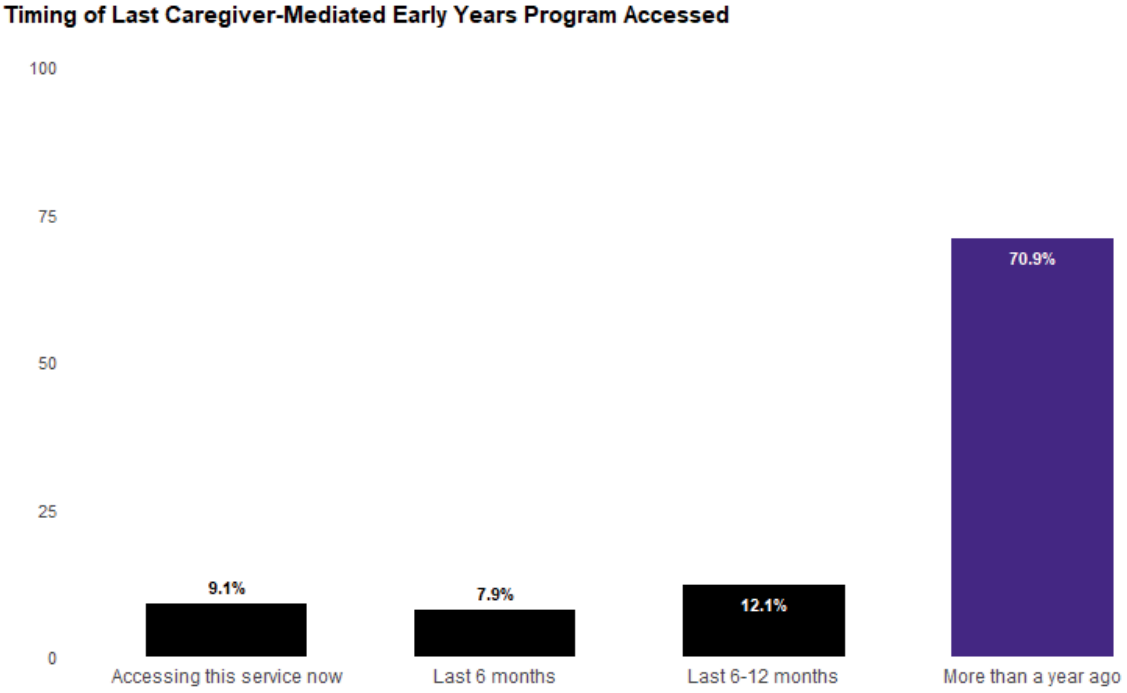
When did you last access Caregiver-Mediated Early Years Programs?

Families who indicated accessing the Caregiver Mediated Early Years (CMEY) pillar program were asked when they last accessed one of the programs.

The majority of respondents (70.9%) reported accessing the service more than a year ago, indicating that most participants have not engaged with this service recently. Only a small proportion of respondents were accessing it at the time of the survey (9.1%) or had done so in the past six months (7.9%), while 12.1% accessed it within the past 6–12 months.

This pattern suggests that recent uptake of the service is low, and there may be barriers to timely access or ongoing engagement. These data highlight the need to explore why so few families are accessing the service currently or within the past year.

FIGURE 26: The majority of families who have accessed Caregiver Mediated Early Years programs have done so more than a year ago



RESULTS
CAREGIVER-MEDIATED EARLY YEARS PROGRAMS

How satisfied are you with Caregiver-Mediated Early Years programs?

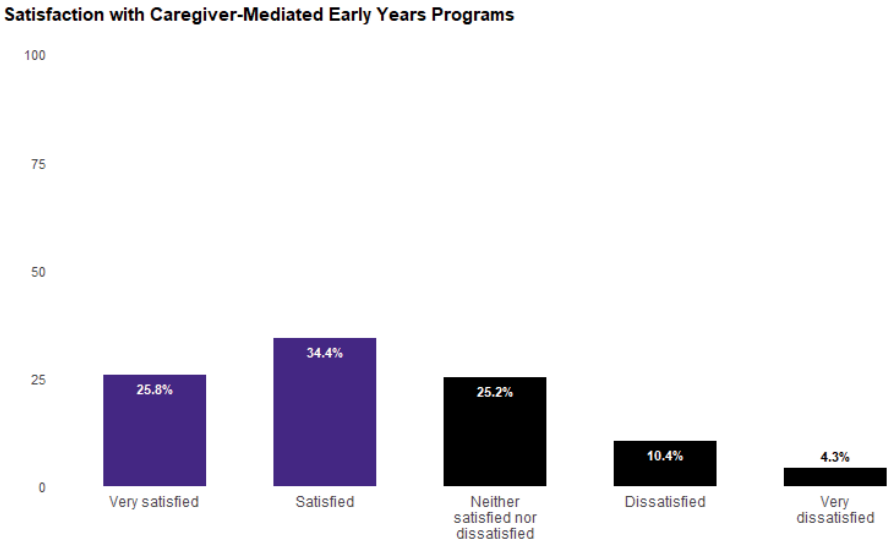
Families who indicated accessing the Caregiver Mediated Early Years (CMEY) pillar program were asked how satisfied they were with those programs.

Overall, most respondents reported positive experiences with the CMEY pillar programs. Over half (60.2%) of participants were either “Very satisfied” (25.8%) or “Satisfied” (34.4%), indicating a generally favourable perception of the service.

Meanwhile, a smaller proportion of respondents expressed neutrality or dissatisfaction: 25.2% were “Neither satisfied nor dissatisfied,” 10.4% were “Dissatisfied,” and 4.3% were “Very dissatisfied.”
These results suggest that while the service is meeting the needs of a majority of participants, there remains a meaningful minority who are neutral or dissatisfied. This highlights the potential to investigate factors contributing to dissatisfaction and identify opportunities for service improvement.

Caregivers’ comments on the Caregiver-Mediated Early Years programs highlight a mix of positive experiences and areas for improvement. Many families valued personalized, in-home support and consistent, collaborative therapists, noting improvements in their child’s communication, regulation, and independence. Programs were often praised for providing useful strategies and resources that parents could apply in daily life. However, respondents consistently noted limitations in program frequency, intensity, and accessibility, with many indicating that one short program per year is insufficient to meet ongoing needs. Some families found virtual delivery less effective, especially for children requiring higher support, and others reported organizational challenges, including scheduling conflicts, last-minute notices, or lack of flexibility. A few participants also noted that programs did not always align with their child’s specific needs or prior experience, limiting the benefit. Overall, while the programs are valued and often helpful, there is a clear need for more frequent, flexible, and tailored supports to better meet families’ needs.

FIGURE 27: More than half of the families who have accessed the Caregiver Mediated Early Years pillar program were satisfied with the service



RESULTS

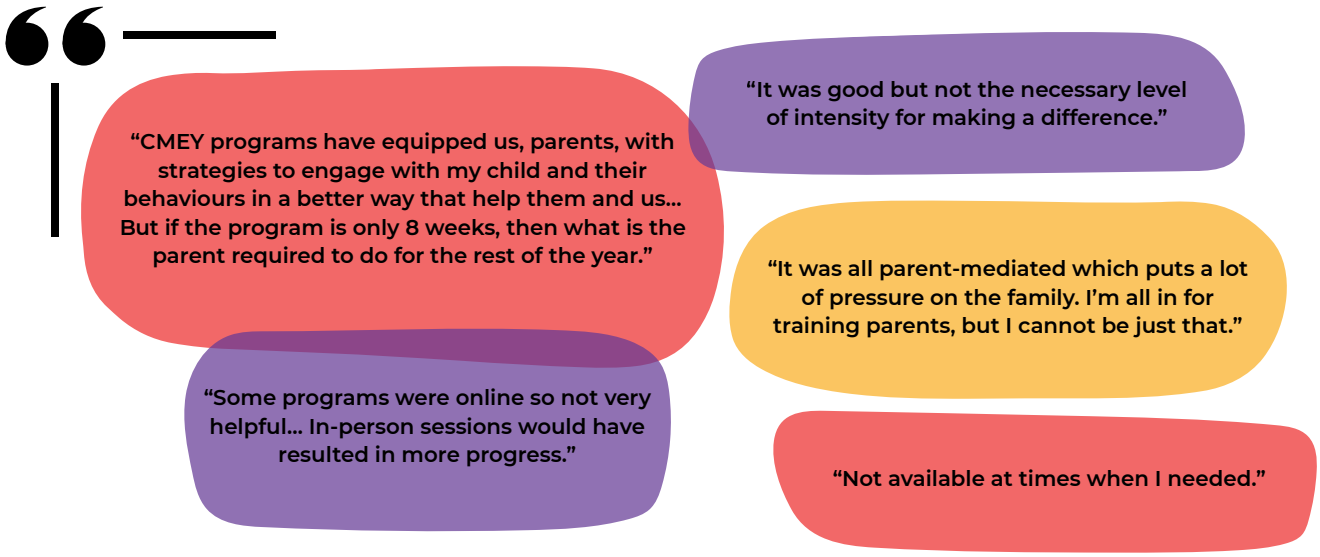
CAREGIVER-MEDIATED EARLY YEARS PROGRAMS

Themes in Satisfaction with Caregiver-Mediated Early Years (CMEY) Programs

Families' satisfaction with CMEY pillar programs varied widely, reflecting differences in program delivery, intensity, and the specific needs of their children. Several key themes emerged:

1. High Satisfaction: Positive Engagement and Practical Strategies: Families who reported high satisfaction highlighted programs that provided hands-on strategies, personalized guidance, and collaborative support from clinicians. Programs that allowed parents to learn actionable skills and adapt interventions to their child's needs were valued highly.
2. Moderate Satisfaction: Limited Impact or Program Intensity: Some families felt that programs were informative but not intensive enough to produce meaningful changes. Short program durations, limited session frequency, or virtual-only delivery reduced the potential impact for children with significant support needs.
3. Low Satisfaction: Access, Delivery, or Fit Issues: Families who were less satisfied reported barriers such as poor communication, inflexible scheduling, virtual delivery challenges, or misalignment with their child's abilities. In some cases, the programs felt generic, redundant, or too parent-led, placing an undue burden on caregivers.
4. Barriers Across Satisfaction Levels: Across all satisfaction levels, several systemic issues were highlighted: programs are sometimes restricted to once per year, limited in duration, and not universally accessible in terms of geography, language, or timing. Families emphasized that more continuous or flexible access could significantly improve outcomes (access to core clinical services funding was mentioned).

Overall, the feedback suggests that CMEY programs can be beneficial, particularly when they are hands-on, personalized, and allow parents to actively support their child. However, program intensity, duration, and accessibility remain major constraints for many families. These limitations place a substantial burden on families, who are often already managing multiple challenges, including work and day-to-day care. Children with the highest support needs are especially left out, as the programs' restricted frequency, short duration, and parent-led format often fail to provide the intensive guidance necessary for meaningful progress.



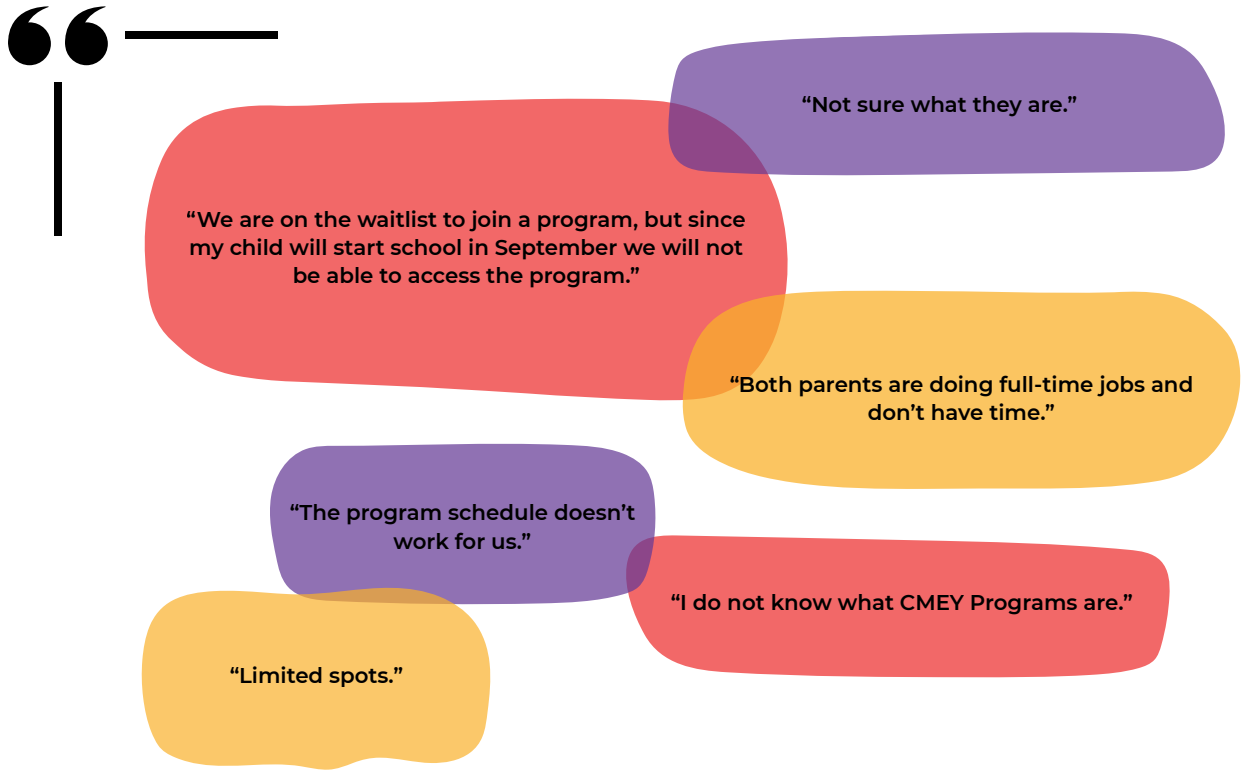
RESULTS
CAREGIVER-MEDIATED EARLY YEARS PROGRAMS

Why Families haven't accessed Caregiver-Mediated Early Years (CMEY) Programs

Survey findings reveal that many families were unable to access Caregiver-Mediated Early Years (CMEY) pillar programs, despite the fact that these services are designed to support children during the most critical period for autism intervention. One-third of families (33.2%) reported never qualifying because of their child's age, nearly one in five (19.9%) said programs were not available in their area, and 4.1% said they did not even know what CMEY programs were. These numbers underline the systemic barriers that continue to block families from reaching the early supports their children need.

In open-ended questions, families reported several recurring barriers to access. Many described children being diagnosed too late to qualify or aging out before ever being offered services. Others noted that CMEY programs were not available in their region or had closed waitlists. Lack of clear information and communication about CMEY prevented some families from even knowing the programs existed. Practical challenges such as multiple assessments, long delays, or program schedules that conflicted with work and caregiving responsibilities further limited participation.

Taken together, these responses highlight a troubling gap: CMEY programs are missing the very children they are intended to support. Instead of timely access to early intervention, families are encountering late diagnoses, regional inequities, poor communication, and restrictive eligibility criteria, leaving many without critical services in their child's earliest years.



RESULTS
CORE CLINICAL SERVICES

What is Core Clinical Services (CCS) funding?

CCS is the key component of the Ontario Autism Program (OAP), designed to provide funding with which to purchase individualized clinical services for autistic children and youth (11). These services aim to enhance the development of communication, social, and daily living skills, and to address challenging behaviours. To be clear, this program does not provide direct clinical services; rather, it provides funding with which families can purchase services, meaning the onus is on the family to understand not only what their child/youth clinically requires but also how to find these services in their region.

The core clinical services include:

- Applied Behaviour Analysis (ABA): A structured approach that uses evidence-based techniques to teach new skills and reduce behaviours that may be harmful or interfere with learning.
- Speech-Language Pathology: Services to support communication development, including speech, language, and social communication skills.
- Occupational Therapy: Assistance in developing skills for daily living and participation in school and community activities.
- Mental Health Supports: Services to address emotional and psychological well-being, including strategies for managing anxiety, depression, and other mental health concerns.

These services can be tailored to meet the unique needs of each child or youth, ensuring that interventions are appropriate and effective. They are delivered by qualified professionals and are available to children and youth registered in the OAP. The goal is to support individuals in achieving their full potential and to promote their inclusion and participation in various aspects of life.

Funding for CCS in the OAP is determined by age and intensity of support needs, but age is a poor measure of actual need, as need can, and often does, fluctuate across the lifespan. This system can actively harm children and youth, as older kids may receive less support precisely when their needs peak, such as during puberty or periods of rapid development. Age-based thresholds risk leaving children under-supported at critical moments, creating unnecessary barriers to care and widening inequities in access to services.

Age Funding Categories and Allocations:

- Up to 3 years old:
  Limited/moderate: $10,900 per year
  Extensive: $65,000 per year
- Ages 4–9:
  Limited: $8,900 per year
  Moderate: $24,500 per year
  Moderate+: $36,800 per year
  Extensive: $65,000 per year
- Ages 10–14:
  Limited: $7,600 per year
  Moderate: $18,800 per year
  Extensive: $41,400 per year
- Ages 15–17:
  Limited: $6,600 per year
  Moderate: $18,300 per year
  Extensive: $31,900 per year

RESULTS

CORE CLINICAL SERVICES

Who is accessing Core Clinical Services (CCS)?

Of the 906 children and youth represented in the survey who were registered with the Ontario Autism Program (OAP), only 297 (32.8%) had received an invitation to Core Clinical Services (CCS), and just 224 (24.7%) were actively accessing the program at the time of the survey. These findings align closely with data obtained through a Freedom of Information (FOI) request submitted by the Ontario Autism Coalition to the Ministry of Children, Community and Social Services and received in June 2025 (Appendix C.), which showed that as of April 2, 2025, 80,998 children and youth were registered with the OAP, yet only 19,168 (23.7%) were accessing CCS funding.

The survey also found that the average age of children and youth accessing CCS funding was 13.5 years, with a median age of 13. This indicates that the program is failing to reach younger children, despite the well-established importance of early intervention. Notably, even the architects of the CCS model acknowledged this priority by allocating larger funding amounts to the youngest age brackets, a design principle that is clearly not being realized in practice (11).

Instead, the age distribution skews heavily toward older youth: only 24.5% were between ages 4–9, while 61.1% were 10–14 years old, and 14.4% were 15–17 years old. Families cannot access Core Clinical Services because they are stuck on lengthy waitlists under the Ministry of Children, Community and Social Services (Appendix B.). As a result, children are aging out of higher funding brackets while still waiting for access to this important program.

This pattern highlights a critical gap: in Ontario, early intervention is not being delivered at the time it is most effective, and CCS is instead serving older youth who have been failed by delays in the core autism program.

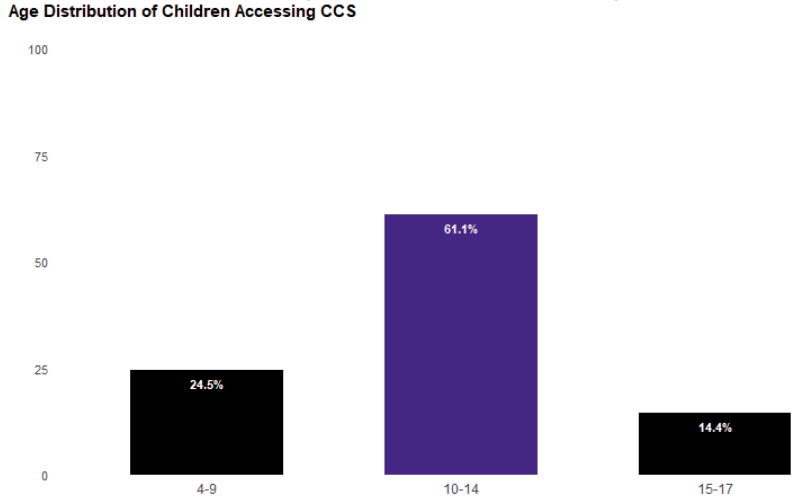
When comparing how many families across different regions have signed a CCS agreement, we didn't find any major regional differences. Families in every region had fairly similar access, proportionately. While families in the West region were a bit less likely to have a signed agreement compared to those in Central or Eastern Ontario, the difference wasn't large enough to be considered statistically meaningful. Overall, this means that families across the province are having roughly the same experiences when it comes to accessing CCS.

INVITED TO CCS
32.8%

ACCESSING CCS FUNDING
24.7%

AVERAGE AGE ACCESSING CCS FUNDING
13.5 YRS

FIGURE 28: The majority of children and youth accessing Core Clinical Services funding at the time of the survey were between the ages of 10-14



RESULTS
CORE CLINICAL SERVICES

Families' experience with Core Clinical Services (CCS) Determination of Needs (DON) process:

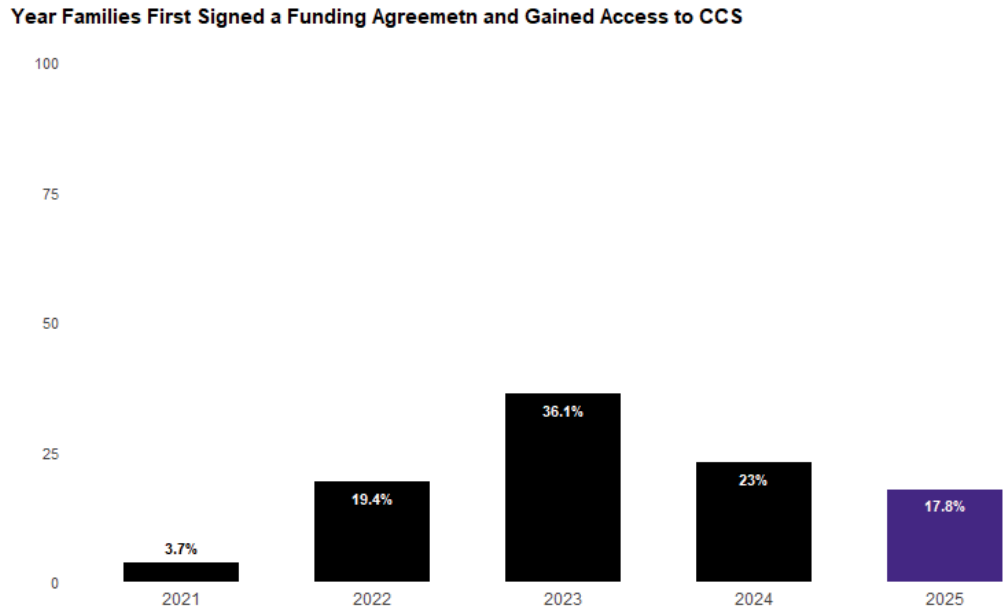
Of the survey's total 906 children and youth who were registered to the OAP, 242 had EVER had a DON meeting (26.7%). The gap between the number of children and youth who have EVER had a DON and those actively accessing CCS funding (2%) is an estimate of those who are in bureaucratic limbo, awaiting CCS funding. These children and youth are not accessing services because they have not yet received funding.

The data on first-time access to Core Clinical Services shows a notable trend over the past few years. Most families first gained access between 2022 and 2024, with the highest proportion (36.1%) starting in 2023. Access in 2021 was very low, representing just 3.7% of the cohort, and the numbers for 2025, while highlighted in the plot, are already lower than the 2023 peak.

This pattern suggests that the number of children entering the Core program has slowed. With over 84,000 children and youth registered in the system (Appendix B.), most of whom are waiting for access to CCS (approximately 64,000), this trend is the opposite of what is needed. Rather than expanding access, fewer new children are starting each year. The lower counts in 2021 and 2025, combined with the concentration in 2023–2024, indicate both a backlog from earlier years and a potential current bottleneck in intake. Families are waiting longer to gain access, underscoring systemic delays and the urgent need to expand Core services.

This trend aligns with what we observe in the community: the rate of new registrations is outpacing the availability of CCS funding. Families continue to enter the system, but access to the supports they need is delayed, creating growing waitlists and extended periods without essential services. Our community data and the accompanying infographic illustrate this mismatch, highlighting the widening gap between children and youth who are registered and those who are actually receiving Core funding.

FIGURE 29: The rate of entry into active funding agreements (access to CCS funding) has decreased since 2023



RESULTS
CORE CLINICAL SERVICES

Age at time of entry to Core Clinical Services Funding:

Analysis of the age of entry into the CCS funding program shows that children are often accessing support later than ideal. The average age at entry is 11.8 years, with a median of 10.7 years. The largest proportion of children (46.7%) enter services between ages 10 and 14, while only a small number (4.4%) enter as adolescents aged 15–17, and very few enter during early childhood (ages 0–3). In fact, this number was so small it was deemed unreportable for ethical purposes.

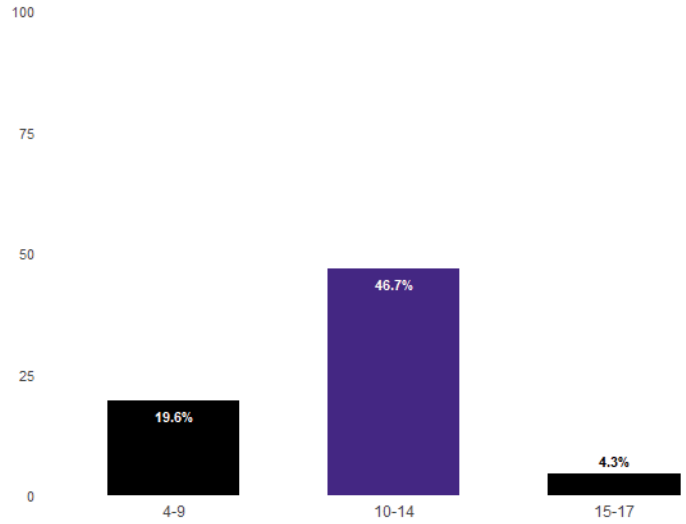
Starting consistent autism services at these later ages can be problematic, as critical periods for social, cognitive, and language development have already passed, making it harder for clinical services to have maximum impact (12). Halbur, Frampton, and Nichols (2025) argue that the timing, intensity, and individualization of early intervention are key determinants of long-term success. They conclude that while methods have evolved, from rigid discrete-trial models to more naturalistic, child-centred teaching, early, well-coordinated, and consistent intervention leads to durable gains in communication, adaptive functioning, and independence (12). The authors also highlight the need for ongoing family involvement and system-level supports to maintain and generalize those gains across settings and over time. The chapter's conclusion emphasizes that early intensive behavioural intervention remains one of the most effective and evidence-supported approaches for improving developmental outcomes in autistic children.

Overall, these findings suggest that many children are not receiving timely access to core clinical supports, potentially missing opportunities for early intervention.

AVERAGE AGE OF ENTRY INTO CCS FUNDING PROGRAM

11.8 YRS

FIGURE 30: Almost half of children and youth with CCS funding first accessed it between the ages of 10 and 14



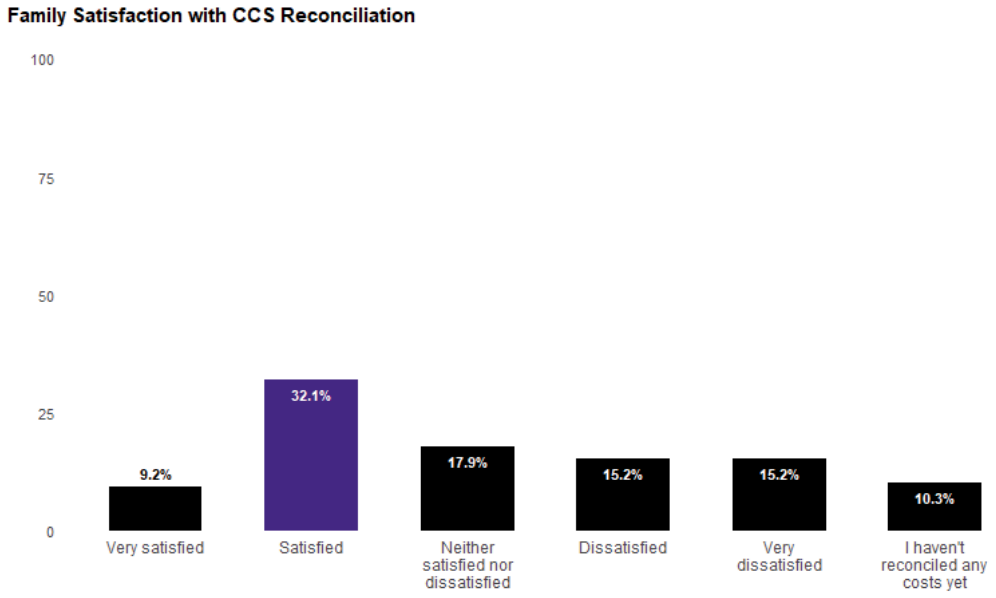
RESULTS
CORE CLINICAL SERVICES

If you have begun spending the core clinical services funding, are you satisfied with the reconciliation process online?

Families accessing CCS were then asked to indicate their satisfaction with the online expense reconciliation process.

Analysis of families' satisfaction with CCS cost reconciliation shows a wide range of experiences. The largest proportion of families (32.1%) reported being "Satisfied," while smaller numbers were "Very satisfied" (9.2%) or "Neither satisfied nor dissatisfied" (17.9%). Notably, 15.2% of families reported being "Dissatisfied" and another 15.2% "Very dissatisfied," and 10.3% indicated they had not yet reconciled any costs. These results highlight that while some families feel positively about the reconciliation process, a substantial number experience dissatisfaction or have not had the opportunity to complete it, suggesting inconsistencies in support and communication.

FIGURE 31: CCS cost reconciliation: many families satisfied, but significant dissatisfaction remains



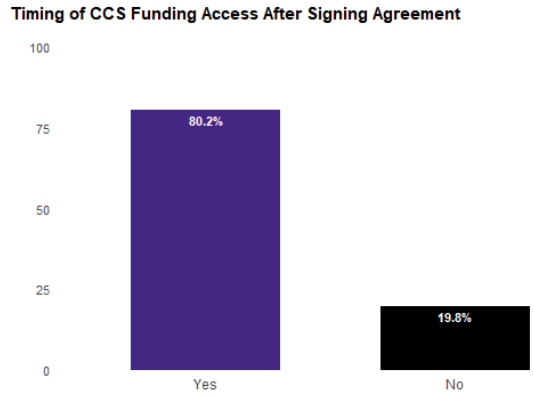
RESULTS
CORE CLINICAL SERVICES

After signing your latest core clinical services contract, did you receive your funding in the time frame that was given to you by the ministry?

Families accessing CCS funding were then asked to indicate if their wait for funding to be deposited was within the timeframe given by the ministry, after signing their service agreement.

Analysis of the timing of access to Core Clinical Services (CCS) funding shows that the majority of families (80.2%) reported receiving funding in a timely manner, while nearly one in five families (19.8%) indicated that they did not. This suggests that although most children are able to access CCS funding when needed, a significant minority experience delays, potentially impacting the supports they can receive.

FIGURE 32: Most families received funding in the time frame given to them by the minsitry

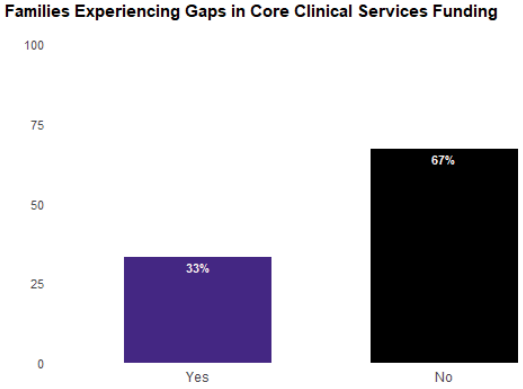


Have you experienced any gaps in funding due to administrative reasons?

Families accessing CCS funding were then asked to indicate if they had experienced any gaps in receiving their funding blocks. CCS funding isn't given in one lump sum; families get it in blocks.

Analysis of CCS funding gaps shows that a significant portion of families experience challenges. Among respondents with signed agreements, one-third (33%) reported experiencing gaps in accessing funding, while 67% did not report gaps. This indicates that although most families are receiving funding on time, a substantial number do not, and that may prevent timely or adequate access to essential services, highlighting ongoing inequities in support provision. This aligns with anecdotal evidence the OAC has received from families, with some indicating loss of placements at providers due to these waits.

FIGURE 33: A third of families experienced delays in funding blocks



RESULTS
CORE CLINICAL SERVICES

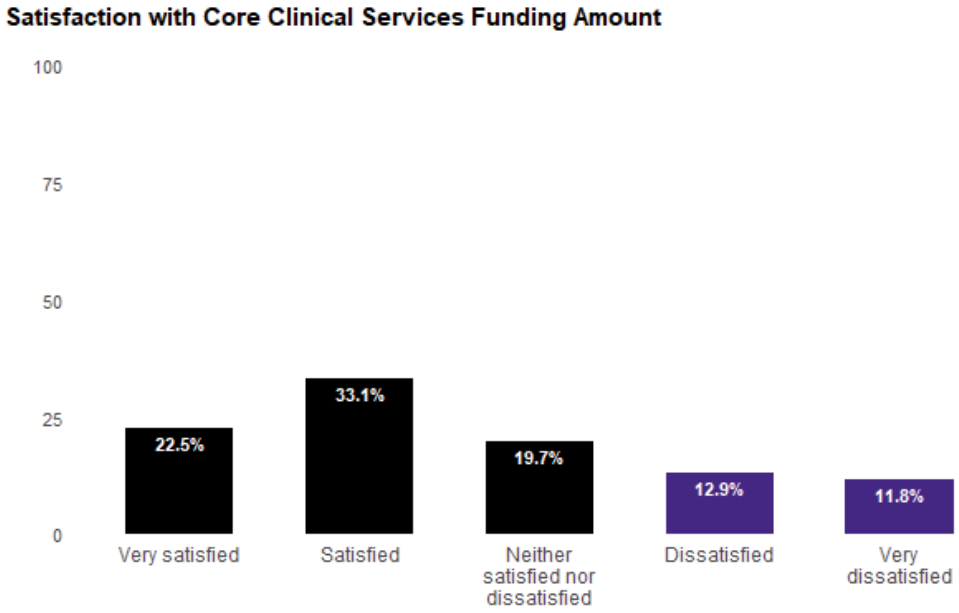
Satisfaction with Core Clinical Services Funding Amount

Families accessing CCS funding were asked to indicate their level of satisfaction with the amount of funding their child or youth received.

When asked about their satisfaction with the amount of Core Clinical Services funding their family member received, responses were mixed. While one-third (33%) of respondents reported being satisfied, only 22% said they were very satisfied. Nearly one in five (20%) were neutral, and about a quarter (25%) expressed dissatisfaction (13% dissatisfied and 12% very dissatisfied).

Overall, fewer than six in ten families reported any level of satisfaction, suggesting that many families continue to experience significant financial strain or perceive the available funding as insufficient to meet their child's clinical needs.

FIGURE 34: A quarter of families reported dissatisfaction with the amount of CCS funding their child received



RESULTS
CORE CLINICAL SERVICES

Does the amount of Core Clinical Services Funding you receive cover all of your/your child's CLINICAL services costs?

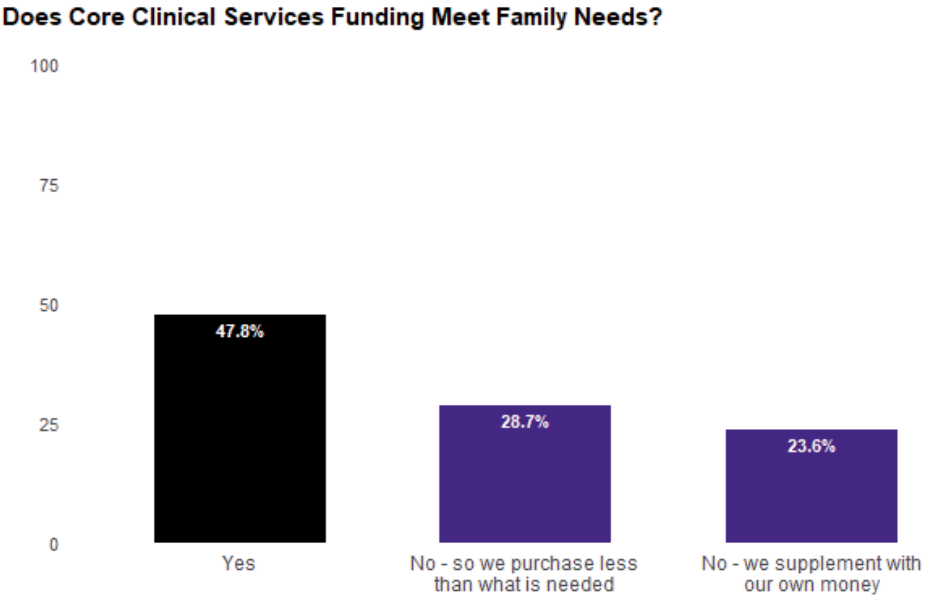
Families accessing CCS funding were asked to indicate whether their funding amount covers their own clinical needs, or those of their child or youth.

Just under half of respondents (47.8%) reported that their Core Clinical Services (CCS) funding meets their child's needs, while more than half indicated that it does not. Nearly one in three families (28.7%) said they are forced to purchase less than what is needed, and almost a quarter (23.6%) reported supplementing funding with their own money to make up the shortfall.

This highlights a critical gap between the level of support provided and the actual costs of clinically necessary services. Families are either scaling back essential therapy or bearing significant out-of-pocket expenses, underscoring the financial and emotional strain created by underfunded allocations.

Anecdotally, the OAC does hear from families frequently discussing costs associated with therapies, and costs are rising. At the same time, CCS funding allotments have never increased since their inception, meaning families are accessing less clinical support now.

FIGURE 35: Half of families reported that the amount of CCS funding their child received does not meet their child's needs



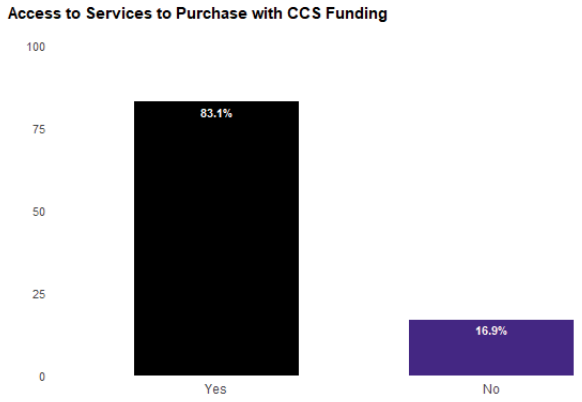
RESULTS
CORE CLINICAL SERVICES

Are you able to access services in your region at which to spend the Core Clinical Services Funding?

Families accessing CCS funding were asked to indicate whether they have access to clinical providers where they can purchase services.

Most respondents (83.1%) reported that they were able to access a provider for Core Clinical Services, suggesting that a majority of families have at least entered the funding stream. However, nearly one in six families (16.9%) indicated that they were unable to access funding at all, a significant concern given the long wait times and administrative complexity of the Ontario Autism Program. This gap highlights persistent barriers to equitable access, even for families who have been deemed eligible, and suggests that the transition from registration to funding approval remains a major point of system failure.

FIGURE 36: Almost 17% of families have nowhere to spend CCS funding

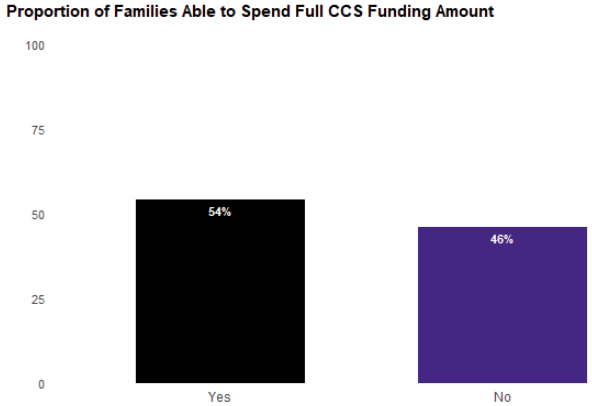


Are you able to spend all of your Core Clinical Services Funding?

Families accessing CCS funding were asked to indicate whether they can spend all of it.

Slightly more than half of respondents (54%) reported that they were able to spend all of their funding, suggesting that at least half have access to providers that have capacity and appropriate services. However, the other nearly half (46%) indicated that they were unable to spend all of their funding; a significant concern. This gap also highlights persistent barriers to equitable access, even for families who have been deemed eligible, have funding in hand, and still cannot spend all of their funding. This suggests that the services landscape is not sufficient to meet the needs of the community.

FIGURE 37: Almost half of families are unable to spend all of their CCS funding



RESULTS
CORE CLINICAL SERVICES

What do you spend your Core Clinical Services Funding on? (choose all that apply)

Families accessing CCS funding were asked to indicate which clinical services they purchase with their funding.

When asked which Core Clinical Services (CCS) funding categories they accessed, most respondents reported using multiple types of support. Nearly half (48%) accessed three or four categories of service, suggesting that many have complex needs requiring a combination of clinical services. The most frequently accessed categories were Applied Behaviour Analysis (64.3%), Occupational Therapy (58%), and Speech-Language Pathology (54.5%), while fewer families accessed mental health supports (32.1%). Many also used funding for items required for therapy (44.6%) or for travel to get to clinical services (39.7%). Notably, travel costs can consume a significant portion of a family's budget, reducing the funds available for direct services, meaning that even with this assistance, many families remain unable to access the full range of supports their children require.

ACCESSED ABA
64.3%

ACCESSED OT
58%

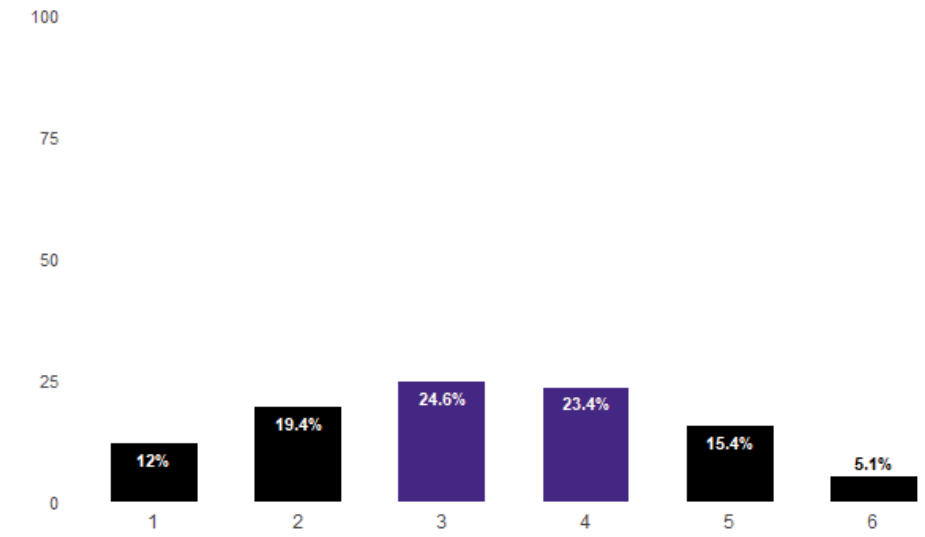
ACCESSED TRAVEL
39.7%

ACCESSED SLP
54.5%

ACCESSED MENTAL HEALTH SUPPORT
32.1%

ACCESSED ITEMS FOR CLINICAL THERAPY
44.6%

FIGURE 38: Almost half of families access a 3-4 different CCS eligible services



RESULTS
APPLIED BEHAVIOURAL ANALYSIS

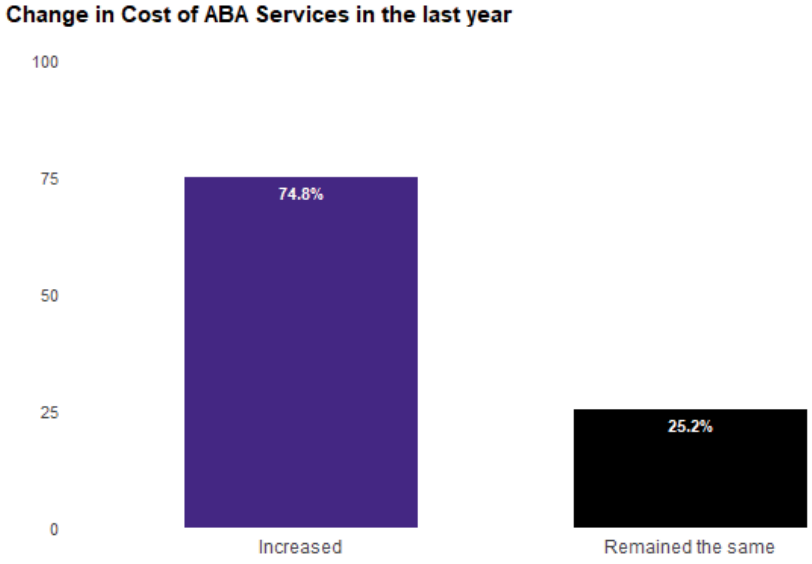
If you or your child are receiving Applied Behavioural Analysis (ABA) therapy, has the cost of these services changed in the past year?

Families who indicated that they were accessing ABA with their CCS funding were then asked if the cost of those services had increased, decreased, or stayed the same in the last year.

Among families reporting on changes in ABA service costs in the last year, the majority (74.8%) indicated that costs increased, while about one-quarter (25.2%) reported that costs remained the same. Very few families reported a decrease in costs, so few that the number is too small to report for ethical reasons.

These findings are compounded by the fact that funding levels in the CCS program have not increased since its inception, despite inflation. As a result, most families accessing ABA are effectively receiving less therapy for the same funding, placing additional financial and service burdens on families.

FIGURE 39: Almost three-quarters of families accessing ABA therapy report that the cost of those services had increased IN THE LAST YEAR



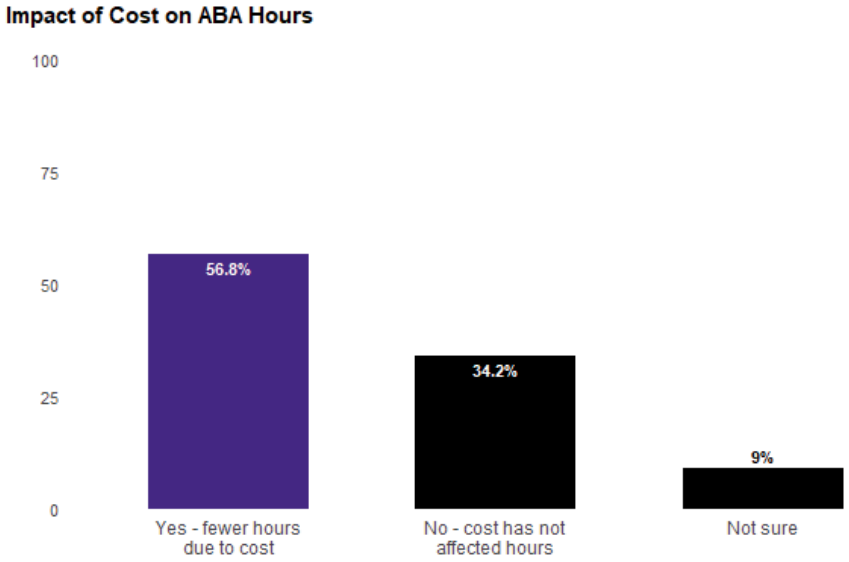
RESULTS
APPLIED BEHAVIOURAL ANALYSIS

Has the cost of ABA therapy had any impact on the number of hours of therapy you/your child receive?

Families who indicated that they were accessing ABA were then asked if the cost of those services had impacted the amount of therapy they were able to purchase.

Analysis of the impact of cost on ABA therapy shows that a majority of families are experiencing reductions in service. Among those responding, 56.8% reported receiving fewer hours of ABA therapy due to cost constraints, while 34.2% indicated that costs have not affected their therapy hours. A smaller portion (9.0%) was unsure of the impact. For ethical reasons, the number of families reporting an increase in hours was too small to report (fewer than 5). These findings underscore that families are not only losing therapy hours due to cost pressures but also that, due to the ministry never having increased funding levels in the CCS categories, families are effectively receiving less support for the same funding year after year.

FIGURE 40: More than half of those families accessing ABA therapy say the cost of therapy has led to them accessing fewer hours of this clinical service



RESULTS
CORE CLINICAL SERVICES DON APPEALS

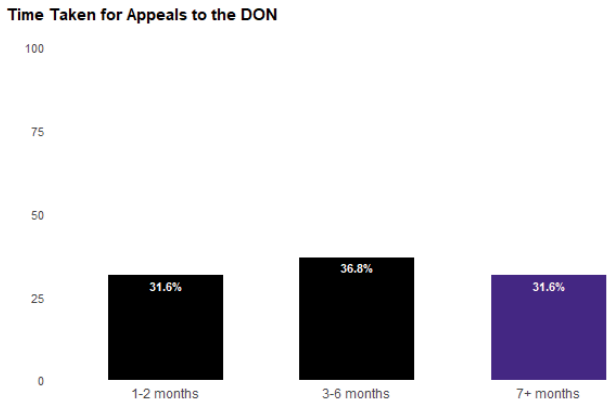
How long did your most recent DON appeals process take?

Families who indicated having completed a DON appeal process were asked how long that process took.

Of those families who have access to CCS funding, approximately 10.3% indicated ever accessing an appeal process for a DON decision.

Analysis of the time families waited for appeals shows that delays are common and highly variable. Among respondents, 36.8% of appeals were resolved within 3 to 6 months, 31.6% within less than 2 months, and another 31.6% took 7 months or longer. The fact that nearly one-third of families waited seven months or more demonstrates that prolonged delays are a significant issue, potentially postponing access to crucial clinical services. Funding agreements have a one-year duration - meaning that when a DON appeal takes longer than expected the timeframe for allowed spending is then compressed for a family. These findings highlight the need for improvements in the timeliness of the appeal process to ensure families receive timely resolution and access to services.

FIGURE 41: A third of families reported CCS DON appeals taking more than ½ a year to resolve.

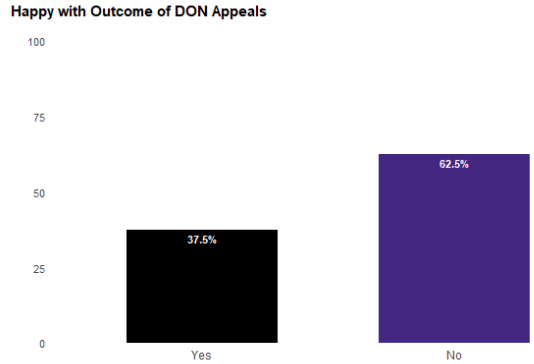


Did the outcome of your most recent DON appeal meet your expectations?

Families who indicated having completed a DON process were asked if they were happy with the outcome of that process.

These data show that a majority of families (62.5%) were not happy with their DON appeal decision, while only 37.5% were satisfied. The high proportion of unsuccessful appeals underscores the need for a review of the appeal procedures, the DON tool itself, and consideration of systemic barriers that may prevent families from accessing the services they are entitled to.

FIGURE 42: 62.5% of families were not happy with their DON appeal outcome



RESULTS
ADULT SERVICES

Adult Services Pilot Questions:

In this pilot set of questions targeting adult services, only a very small number of respondents were adults, limiting the depth of conclusions that can be drawn.

Among this specific cohort, access to supports is highly variable:

- Less than 5 are accessing housing
- 92% are accessing Passport funding
- 15% are accessing day programs
- Nearly all are accessing ODSP

Open-text responses indicate that some families are paying out of pocket for ABA or social programs, behavioural therapy, respite, or urgent services. Several respondents noted being on waitlists for services, including supported independent living housing, or reported that their adult family member does not appear to qualify for any services at all. Other responses highlighted difficulties navigating the system, including accessing adult psychiatry or obtaining connections through Developmental Services Ontario.

These early findings point to the need for a more in-depth adult-focused questionnaire in the future to better understand service gaps and access challenges.

RESULTS
RESPITE

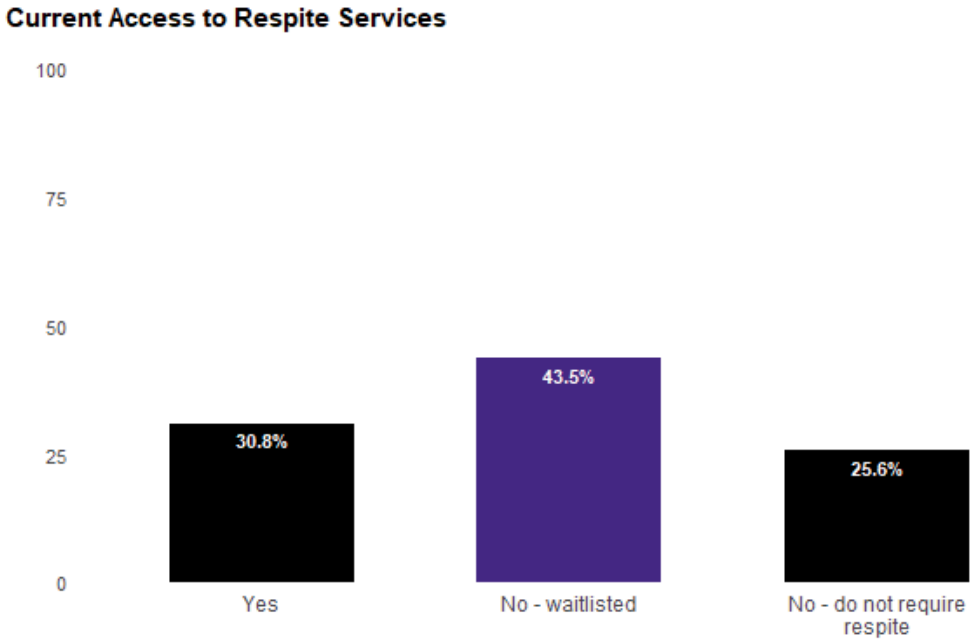
The OAP does not include respite. Are you currently receiving ANY respite services?

All survey respondents were asked about their access to respite at the time of the survey; 827 answered this question.

The survey results indicate that a significant proportion of families are currently waiting for respite services. Of the respondents, 43.5% reported being waitlisted, while 30.8% are currently receiving respite support. About a quarter of families (25.6%) indicated they do not require respite at this time.

This highlights a substantial unmet need for respite services in the community, with nearly half of families unable to access timely support, which can contribute to increased caregiver stress, burnout, and reduced capacity to support their family members.

FIGURE 43: Almost half of respondents need respite support but cannot access it due to waitlists



RESULTS
RESPITE

Please indicate what respite services you have access to. (choose all that apply)

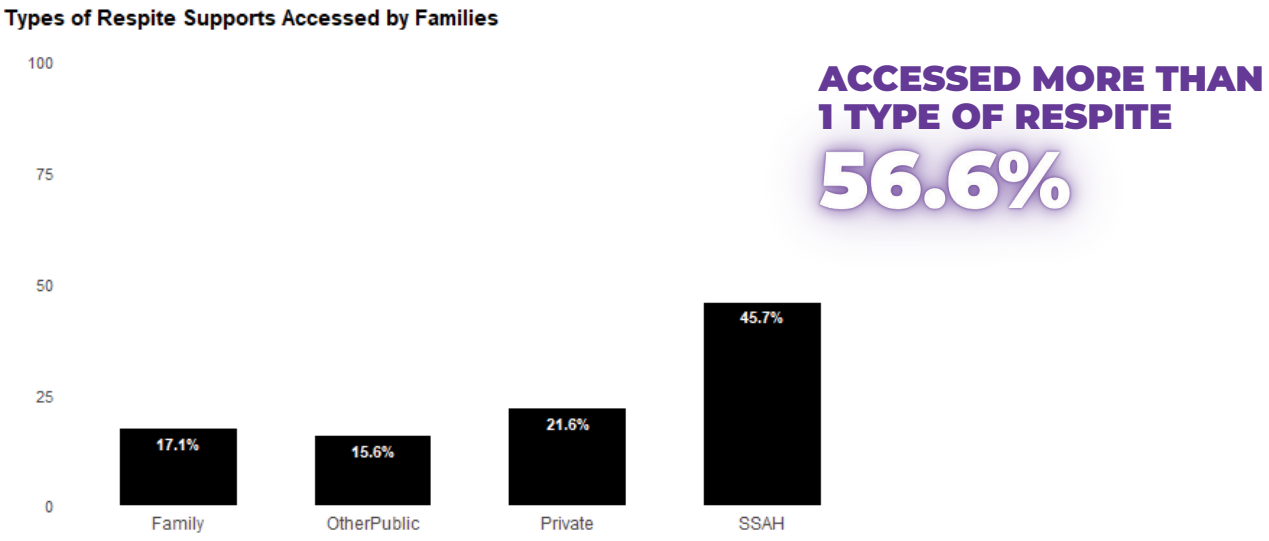
Families that indicated accessing respite were then asked what type of respite they were accessing.

The survey data show that families are accessing a variety of respite supports, with the highest proportion (45.7%) receiving SSAH funding. Smaller proportions are accessing other public respite programs (15.6%), private respite services (21.6%), and support from family members (17.1%). This indicates that while SSAH remains the most commonly used support, many families are relying on a combination of other public, private, and family-based respite options to try and meet their needs. The diversity of supports accessed also highlights gaps in availability and accessibility, as families must often piece together multiple types of services to ensure adequate respite for their child or youth.

The data indicate that families often rely on multiple types of respite supports to meet their needs. While 43.4% of families access only one type of respite, a significant portion are using two (33.6%), three (18.4%), or even all four types of respite (4.5%). This suggests that many families cannot rely on a single source of respite to meet their needs, and instead must navigate multiple funding and service streams, reflecting both the complexity of service access they must navigate and potential gaps in availability.

In an open-ended question about "other" sources of respite, respondents reported accessing a wide range of programs, including Complex Special Needs funding, Passport, Autism Ontario supports, and Urgent Response Services. While some families receive meaningful support, many are on waitlists or rely on short-term services, limiting the consistency and hours of respite available. A few families described reducing paid employment or paying out-of-pocket to fill gaps in care. Although only a small portion of the sample was adults, these responses highlight significant challenges in accessing adequate, consistent respite support throughout the lifetime.

FIGURE 44: Almost half of families accessing respite have access to SSAH funding



RESULTS
RESPITE

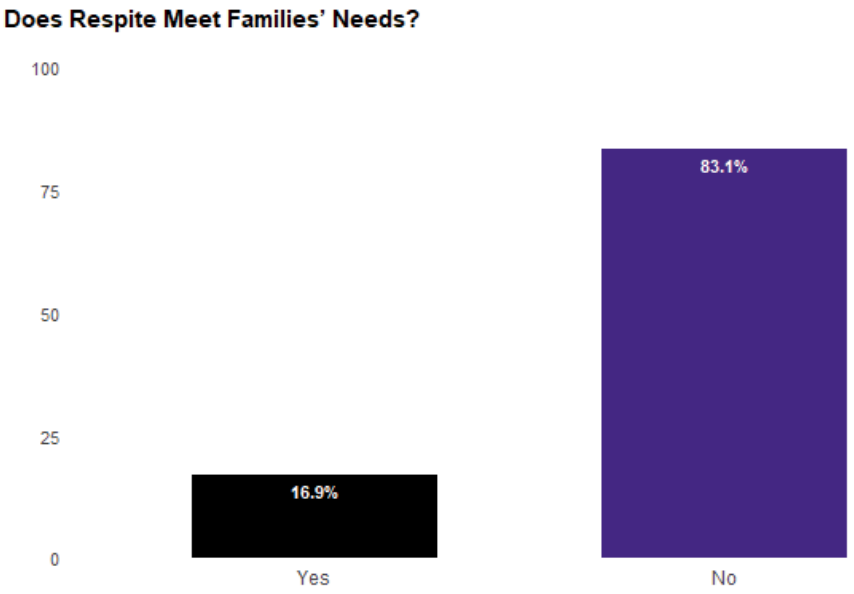
Does the amount of respite you receive meet your family's needs?

Families accessing respite were then asked if the amount of respite they are receiving is meeting their needs.

Only a small minority of families, about 17%, said that the respite services they receive meet their needs, while the vast majority (83%) reported that they do not. This finding points to a significant gap between what families require for meaningful respite and what is currently available through existing systems and funding streams. Families' earlier comments reinforce this pattern, describing fragmented supports, long waitlists, and programs that are too short-term or restrictive to provide real relief. Together, these results suggest that while many families may technically have access to respite, most are not receiving the type, amount, or consistency of support needed to meaningfully improve family well-being and stability.

> **"I'm on the waitlist for SSAH and while waiting on receiving it from Family Services in my town, it's not a lot but it helps."**

FIGURE 45: Of families accessing respite, the majority do NOT feel that the respite services are meeting their needs



RESULTS
RESPITE

If you are accessing public respite funding, how long did you wait for access?

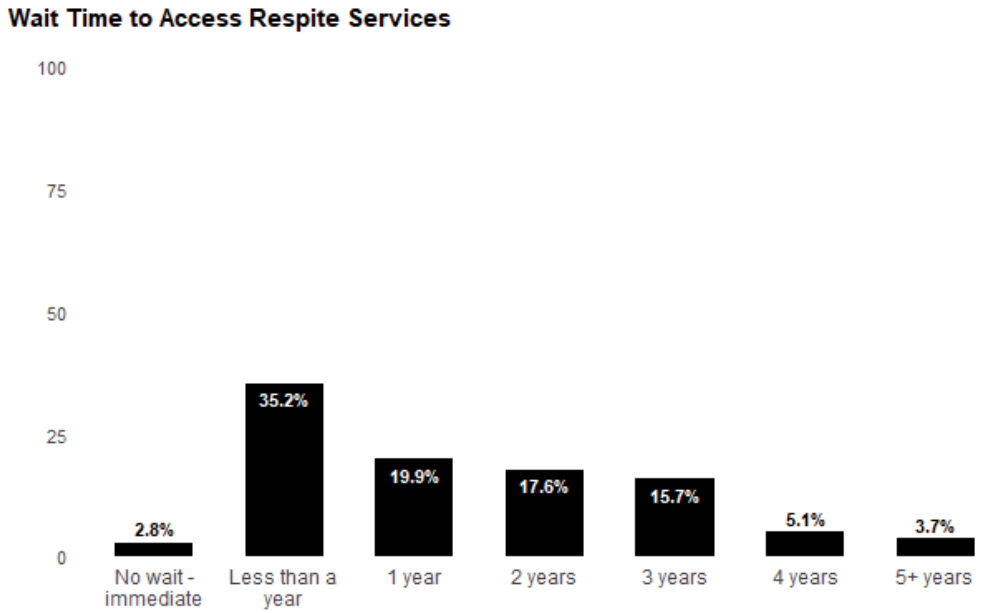
Families accessing public respite streams were then asked how long they had to wait to access the service.

Analysis of respite wait times shows that the majority of families experience substantial delays in accessing services. While a small proportion (approximately 3%) receive respite immediately, and just over a third (35%) access services within less than a year, more than half of families (approximately 62%) wait one year or longer. Notably, nearly 9% of families wait four years or more.

These extended wait times are concerning because they limit the opportunity for timely support, potentially impacting both caregiver well-being and the developmental progress of the child or youth receiving respite. Research consistently shows that caregivers of autistic children experience higher levels of stress, anxiety, and depression than other parents, especially when they lack access to services or reliable support (13). When families wait years for respite or other forms of relief, that stress compounds, leaving caregivers feeling exhausted, isolated, and less confident in their ability to meet their child's needs. In many cases, when formal supports or funding are not accessible, families are forced to rely on an aging population of grandparents and older relatives to provide care, a situation that places additional strain on extended family networks and is not sustainable in the long term.

Taken together, these results show that for the majority of families, respite is not available in a timely manner. Given that families often rely on this support to maintain stability and prevent crises, multi-year waits for respite are unacceptable and point to systemic service gaps that urgently need to be addressed. Improving timely access to respite and related supports would not only benefit children and youth, but also strengthen the well-being, confidence, and resilience of the caregivers who support them every day.

FIGURE 46: Of families accessing respite, the majority waited over a year to access that support



RESULTS
SCHOOL

Does the person you are filling this survey out for presently attend an Ontario School?

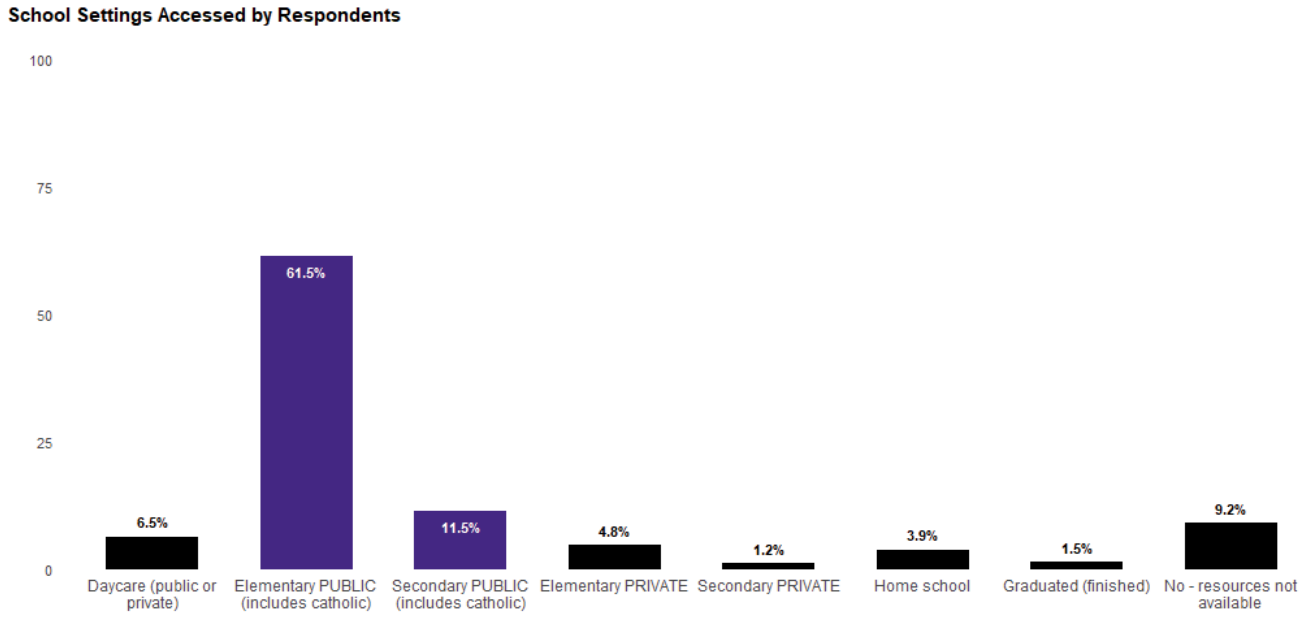
Respondents were then asked to indicate if the person they were filling this survey out for (themselves or a family member) was attending school at the time of the survey.

Among the 821 respondents who answered this question, the majority are engaged in the public school system, with Elementary PUBLIC (61.5%) and Secondary PUBLIC (11.5%) comprising the largest proportions. A smaller number of respondents access private schooling, homeschool, or daycare, while some have graduated. Concerningly, 9.2% of respondents reported that the person was not attending, despite having the right to, school because the resources they need are not available (14). This aligns with the Canadian Human Rights Commission findings, that about one in ten Canadians with disabilities are being forced to limit their educational and career opportunities, and in some cases, to end their education entirely (14).

Findings from the Ontario Autism Coalition's Special Education Survey (2023–2024) reinforce how widespread these access issues are. The report found that 6% of all special education students were completely excluded from school during the 2023–2024 year, despite being entitled to attend, and that 73% of these exclusions were directly linked to a lack of appropriate accommodations (15). In addition, over one-third (38%) of students on modified schedules were attending reduced hours because schools did not have enough resources to support them safely on a full-time basis.

This indicates that while public education remains the primary setting, a notable minority of families experience systemic gaps in resource availability that prevent students from accessing school consistently or safely. These findings highlight an urgent need for increased funding, staffing, and accountability within Ontario's education system to ensure that no student is left without access to meaningful, inclusive learning opportunities(15, 16).

FIGURE 47: Most respondents indicated current access to public elementary and secondary school



RESULTS
SCHOOL

Is the school able to accommodate appropriately?

Those respondents who indicated access to school were then asked to indicate if the school was able to provide needed accommodations.

Just over half of respondents (52.8%) reported access to needed school accommodations, while 47.2% indicated that they do not. This nearly even split highlights that a substantial portion of students are not receiving the accommodations they need to fully participate in their educational environment. These findings point to persistent gaps in school support that must be addressed to ensure equitable access to learning opportunities (14, 15, 16).

REQUIRED SCHOOL ACCOMMODATIONS UNAVAILABLE

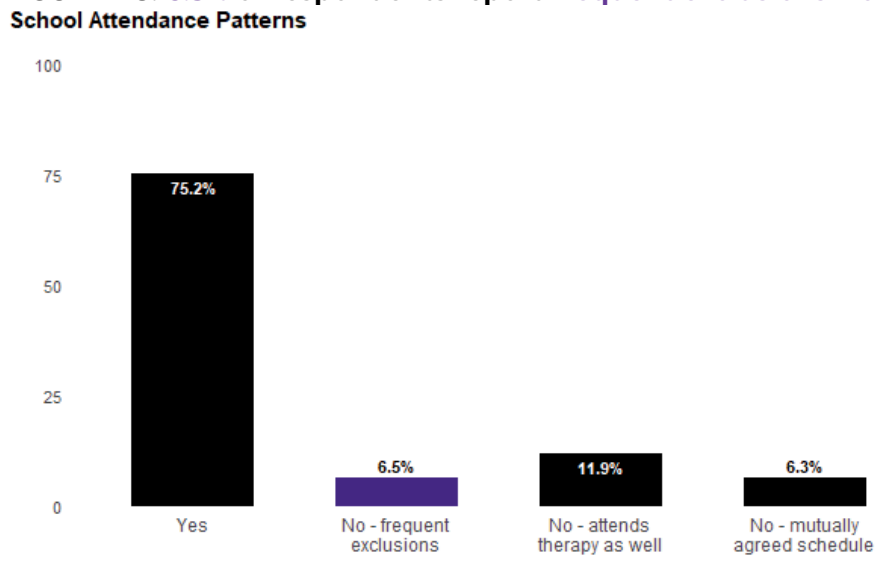
47.2%

Do they attend school full-time?

Those respondents who indicated access to school were then asked to indicate if the student was attending school full time, and if not, why.

The vast majority of students in the sample (75%) are attending school as expected, without interruptions. However, a portion of students are experiencing challenges: about 12% attend school but also participate in therapy during the day, 6.5% experience frequent exclusions, and 6.4% follow a mutually agreed-upon schedule. The data highlight that while most students are accessing full-time education, a notable minority face barriers that disrupt their consistent school attendance, which could have implications for both learning and social development (17).

FIGURE 48: 6.5% of respondents report frequent exclusions from school



RESULTS
SCHOOL

During the school year, have you had any safety concerns at school (OTHER)?

The open-ended responses on full-time school attendance highlight significant challenges in accessing consistent and adequate educational support for autistic students. Many families report that their child attends school only part-time or on a modified schedule, often due to insufficient support, safety concerns, or therapy needs integrated during the day. Frequent exclusions, both formal and constructive, were commonly noted, with some students missing substantial portions of the school year. School avoidance and burnout were also frequently reported, reflecting the strain on children when their needs are not adequately met.

A subset of respondents relies on alternative or specialized programs, such as ABA-integrated schools or preparatory programs, while many parents remain actively involved, sometimes needing to be on call to pick up their child.

Overall, these responses indicate that despite some access to educational programs, many families experience inconsistent attendance and significant barriers to fully inclusive schooling (15, 16, 17).

"They are supposed to attend school, but the two-to-one EA support are untrained, unequipped, and unwilling to keep them all day."

"We were constructively excluded for more than 60% of the school year this past year."

"My child experiences excessive burnout and school avoidance – they miss a lot of school."

"Yes, full time but she needs additional assistance that I do not have the means to pay for."

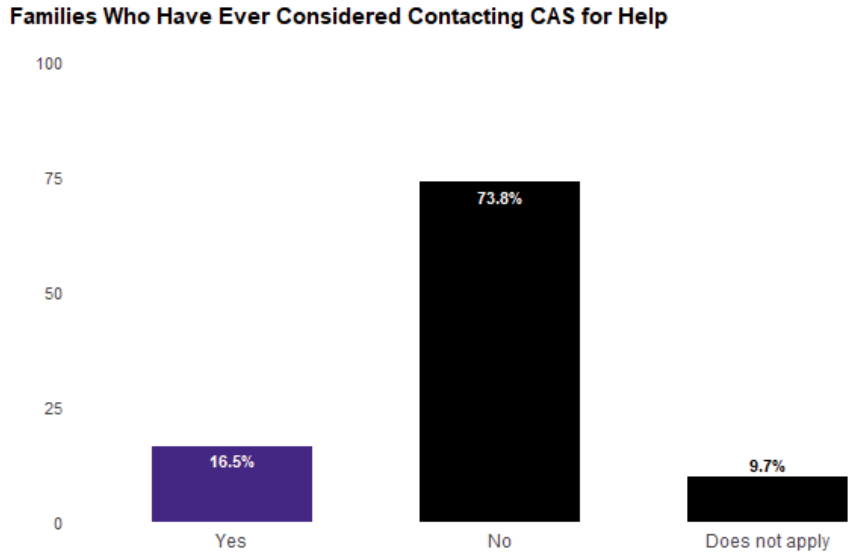
RESULTS
CHILDREN'S AID SOCIETY

At any point in your family's journey, did you ever consider contacting CAS?

Respondents were asked if they had ever considered contacting CAS for help.

Most families (74%) reported that they have not considered contacting CAS for help. A smaller proportion, 17%, indicated that they have considered this option, while about 10% felt the question did not apply to their situation. This suggests that while the majority of families are not engaging with CAS as a potential support pathway, a notable minority are facing circumstances or challenges significant enough to have considered it.

FIGURE 49: 16.5% of families have considered contacting CAS for help



RESULTS
CHILDREN'S AID SOCIETY

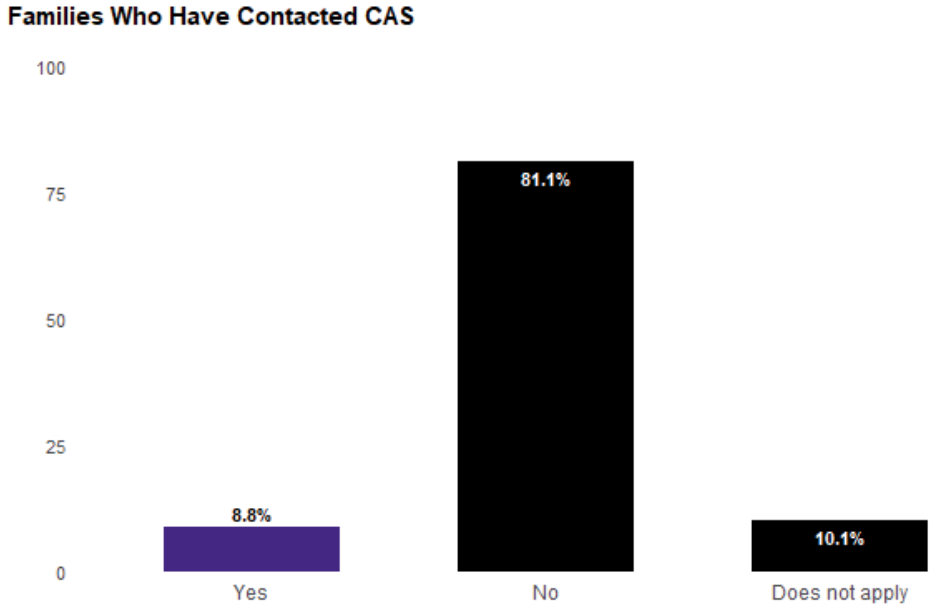
At any point in your family's journey, did you actually contact CAS for help due to a lack of services and/or support?

Respondents were asked if they had ever contacted CAS for help due to a lack of services and/or support.

8.8% of families in the survey have ever contacted a CAS for help. The vast majority, 81.1%, reported that they have not contacted CAS, while 10.1% indicated that the question did not apply to them.

No family should have to contact a CAS organization out of desperation due to a lack of services and support. The fact that nearly 9% of respondents have done so is deeply concerning. In a population of over 84,000 children and youth registered for the Ontario Autism Program, this could represent potentially thousands of families being pushed toward CAS involvement because adequate supports are not available. CAS's mandate is to protect children from harm, not to act as a provider of essential autism or respite services. Yet, due to gaps in the current system, families are being forced into a new pathway towards CAS to try and meet needs that should be addressed through appropriate healthcare, education, clinical services, and community supports. This reflects a system-level failure in which children and youth are experiencing unnecessary risk, and families are left navigating a pathway that they should never have to.

FIGURE 50: Almost 9% of families have needed the help of CAS due to a lack of services and support



RESULTS
CHILDREN'S AID SOCIETY

Did CAS offer you help in the form of child custody?

Respondents who indicated ever contacting CAS for help were asked if CAS offered help in the form of child custody or in another way.

The data show that among families who engaged with CAS, the majority were either not helped directly or were assisted in alternative ways, reflecting the limited capacity of CAS to provide the support families were seeking.

A very small number of families accepted child custody help directly from CAS, while an even smaller number declined the child custody support offered. The totals for both these categories cannot be reported due to small numbers. Several families were unsure or preferred not to say whether CAS provided assistance.

42.4% of families were helped in another way by CAS, other than child custody, and a further 41.1% reported that CAS could not help them at all.

These results suggest that CAS is rarely the primary pathway for resolving service needs, reinforcing the finding that families are seeking help from CAS primarily to fill gaps in available services, rather than for CAS's core child protection mandate.

This question will be asked again in the 2026 OAC Community Survey to watch this occurrence, as many families are approaching the OAC for information about this topic.

RESULTS
MENTAL HEALTH

How would you rate the current mental health of the person you are filling this survey out for?

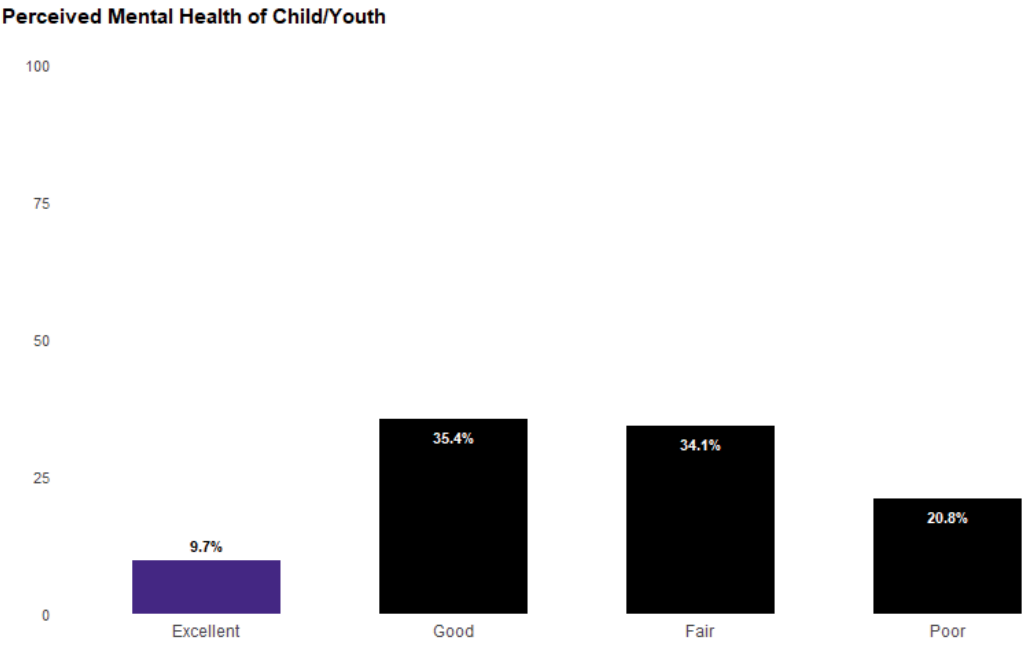
Respondents were asked about the mental health of the person they were filling the survey out for.

When asked to rate the mental health of the person they completed the survey for, the largest proportion of respondents indicated Good (35%) or Fair (34%) mental health, while Poor ratings were reported by 21% of respondents. Only a small proportion rated mental health as Excellent (10%).

These results suggest that while some are thriving, a significant number are experiencing challenges with their mental health, highlighting the importance of targeted supports and interventions.

It's not surprising that many families report mental health challenges in their loved ones after all, there are over 61,000 children and youth in Ontario still waiting for core clinical services, including vital clinical services and supports. According to our survey data, children are waiting until an average age of 13.5 years before they receive any meaningful, consistent help. This means that many spend the majority of their childhood largely unsupported, struggling through critical developmental years without consistent access to support or mental health care. In that context, it is unfortunately not surprising that so many families reported the mental health of their child or youth that is "Fair" or "Poor." These findings make clear that long waits and a lack of early intervention are taking a measurable toll on the well-being of autistic children and youth in Ontario (6).

FIGURE 51: Only 9.7% of respondents rated the mental health of the person the survey was about as excellent



RESULTS
MENTAL HEALTH

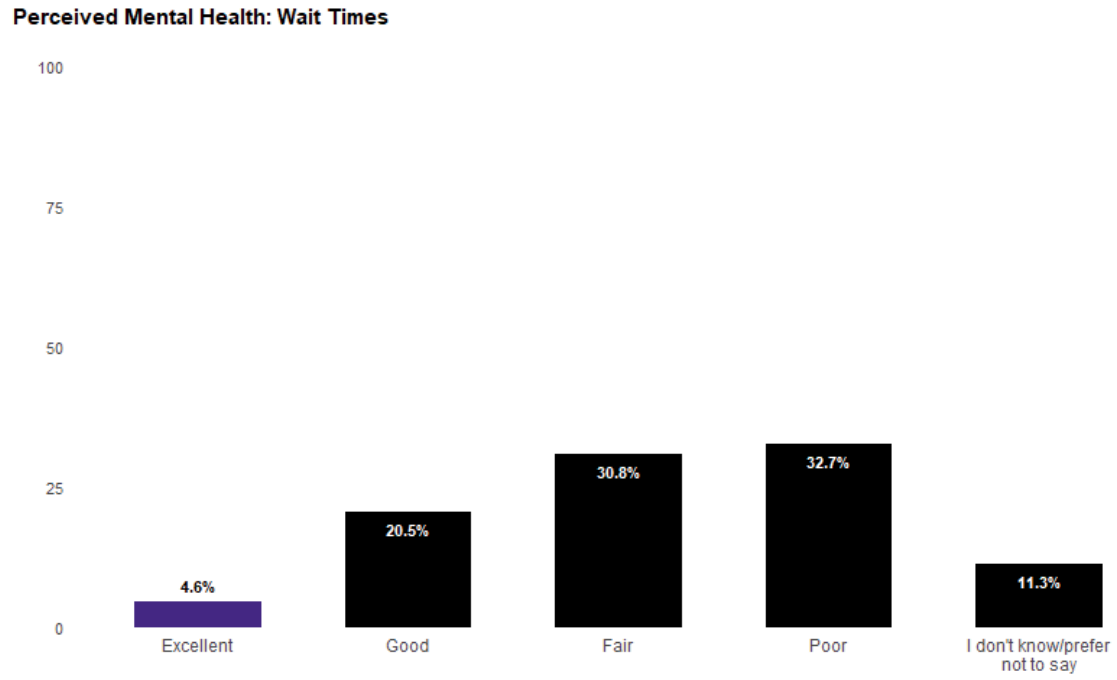
Please rate this person's mental health during the wait for services/support?

Respondents were asked about the mental health of the person they were filling the survey out for, while they were waiting for services/support.

Only a small portion of respondents rated their/their loved one's mental health as "Excellent" (around 5%). The largest groups rated it as "Poor" or "Fair" (together over 60%), indicating that many families perceive wait times as having a significant negative impact on mental health. A smaller portion reported "Good," while some respondents were unsure or preferred not to say. Overall, the results highlight substantial concern about the mental health effects of delays and waiting periods for support.

Again, it's not surprising that many families report mental health challenges; after all, there are tens of thousands of children and youth waiting for core clinical services and autism supports. In Ontario alone, more than 61,000 children remain on waitlists for Core Clinical Services. When services are delayed for years or unavailable, individuals can experience prolonged periods of little to no consistent help, leading to increased stress, disruption, and diminished hope for timely help. In that context, the fact that over 32.7% of respondents rated mental health as "Poor," and another third rated it "Fair," aligns tragically with the burden of long waits. These findings underscore that delays in accessing services are not abstract; they are likely contributing directly to mental health strain among the very people the system is intended to support (6).

FIGURE 52: Only 9.7% of respondents rated the mental health of the person the survey was about, as excellent



RESULTS
MENTAL HEALTH

If you are a parent/caregiver, how would you rate your mental health?

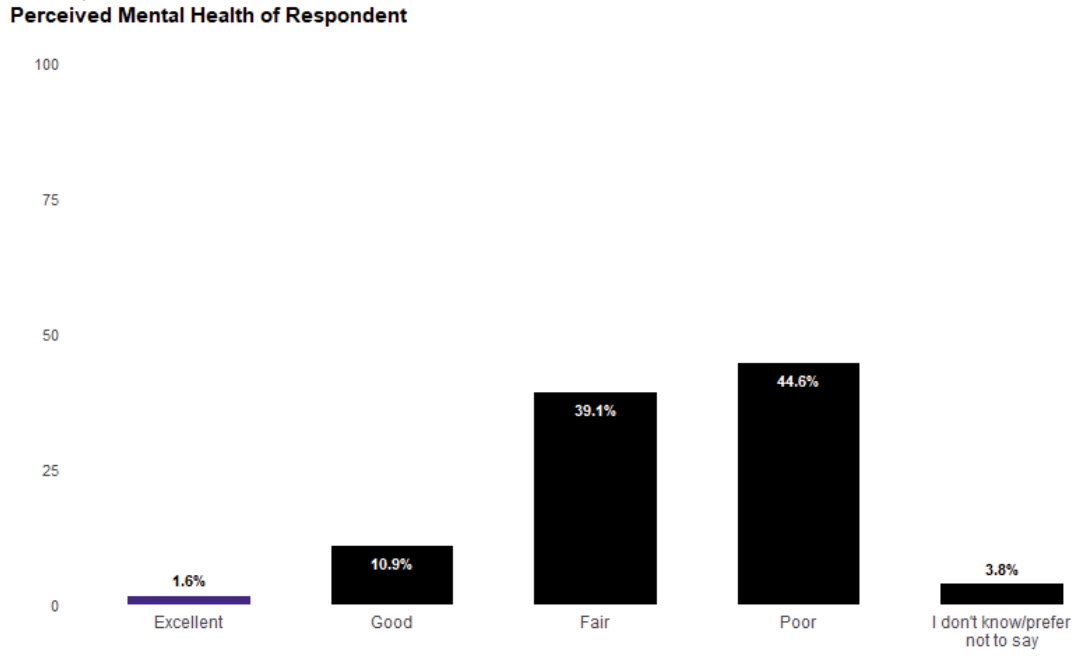
Respondents who identified as parents/caregivers were asked about their own mental health at the time of the survey.

When asked about their own mental health, most respondents rated themselves as Fair (39.1%) or Poor (44.6%), with a smaller proportion indicating Good (10.9%). Very few respondents felt their mental health was Excellent (1.6%), and a small group were unsure or preferred not to say (3.8%).

These results suggest that caregivers completing the survey are experiencing significant stress and mental health challenges, highlighting the strain faced by families.

The long wait for services doesn't just affect children and youth; it takes a heavy toll on their parents and caregivers as well. The emotional, physical, and financial strain of providing round-the-clock care without adequate support can be overwhelming (6, 13, 18). Many families are paying out-of-pocket for therapy or juggling multiple jobs to fill the gaps left by delayed funding, all while managing complex caregiving needs that rarely pause, even for a day (6). The uncertainty surrounding when, or if, support will arrive, compounded by the government's undisclosed timelines for service access, deepens the mental health burden on families already stretched to their limits. Knowing that help exists but remains out of reach adds another layer of stress and heartbreak (13). Yet what remains striking throughout this survey is the depth of love and commitment these families demonstrate. Despite the exhaustion, uncertainty, and financial hardship, they continue to advocate, to show up, and to do everything in their power to support their children. Their perseverance underscores both the urgency of systemic change and the extraordinary resilience within the community.

FIGURE 53: Only 1.6% of respondents rated their mental health as excellent at the time of the survey



RESULTS
MENTAL HEALTH

If you are a parent/caregiver, how would you rate your mental health during the wait for services/support?

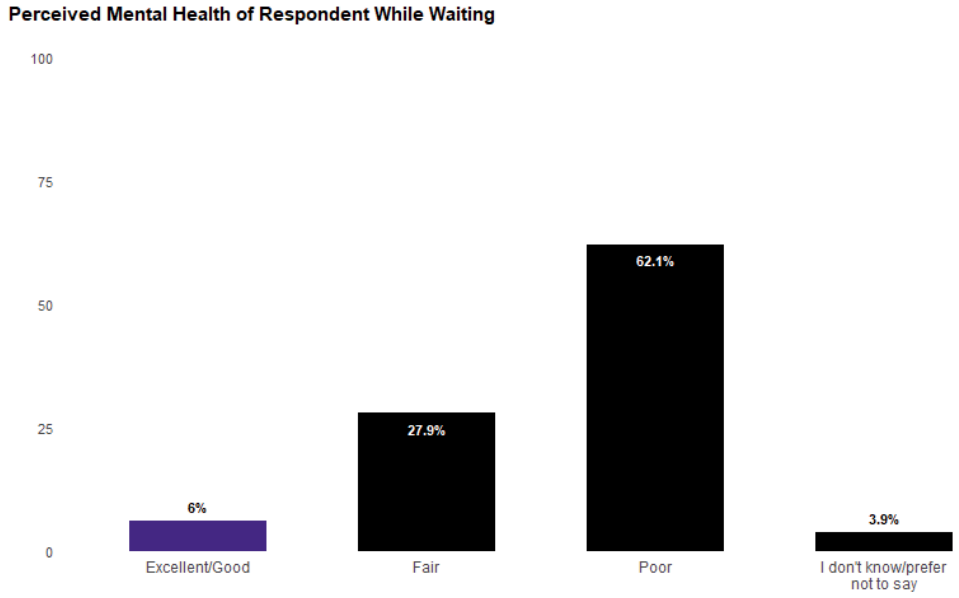
Respondents who identified as parents/caregivers were asked about their own mental health during the wait for services/support for their loved one.

When asked to rate their own mental health while waiting for services for their loved one, a substantial majority of respondents reported challenges. Only 6% rated their mental health as Excellent/Good (which had to be combined for reportability purposes - counts 5 or under), while 28% reported it as Fair. Most concerningly, 62% of respondents indicated their mental health was Poor during this period. A small proportion (4%) selected “I don’t know/prefer not to say.”

These results highlight the considerable stress and strain experienced by respondents while navigating service waitlists, underlining the urgent need for improved support systems.

System delays affect not only autistic children and youth, but also the families who care for them. The wait for services is not a passive experience; it is filled with worry, exhaustion, and financial strain (6, 13, 18). Caregivers often spend years trying to manage complex needs without the professional support their loved one requires, all while balancing work, family responsibilities, and the costs of care that can feel impossible to sustain. Many families shared that the constant demands of caregiving, paired with the uncertainty of long waits, have left them drained and stretched beyond their limits. It is incredibly difficult to know that supports exist that could make life easier for their family member, yet remain inaccessible. Still, the responses reflect something powerful; an enduring strength and devotion. Even in the face of exhaustion and discouragement, parents and caregivers continue to fight for their children’s needs, demonstrating remarkable resilience and love.

FIGURE 54: Only 6% of respondents rated their mental health as excellent/good during periods of waiting for services



***Excellent and Good categories had to be combined for reportability purposes (counts under 5)**

RESULTS
FAMILY LIFE

Has anyone in your household had trouble working or keeping a job because your family couldn't get the services or support you needed?

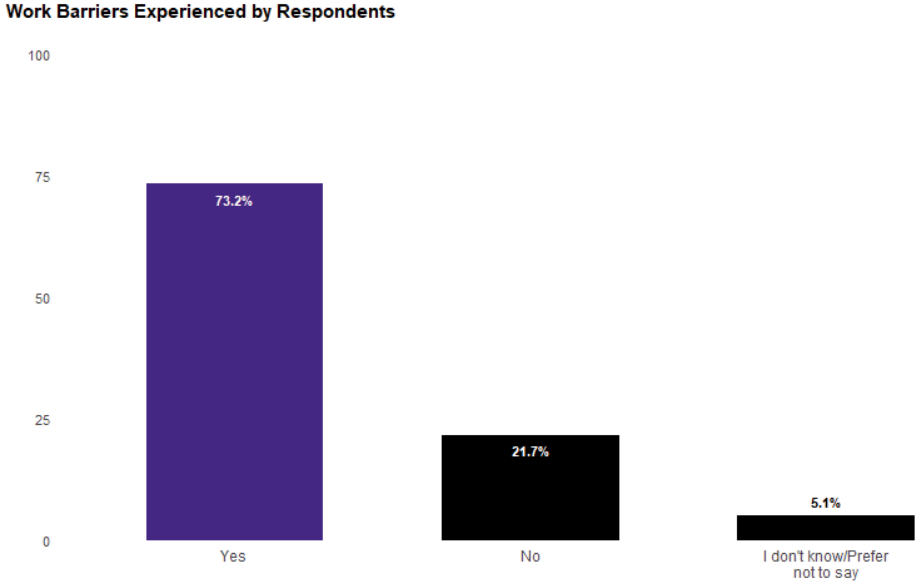
Respondents who identified as parents/caregivers were asked if anyone in their household had trouble working or keeping a job because of a lack of services/support.

The majority of respondents (73.2%) indicated that they experienced barriers to employment related to caring for their child or youth, highlighting the significant impact of caregiving responsibilities on work participation. About one-fifth of respondents (21.7%) reported no work-related barriers, while a small proportion (5.1%) were unsure or preferred not to answer.

This underscores that employment challenges are a common and pressing issue for families in this community, with potential implications for income, career progression, access to services, support, and overall family well-being (6).

Although this survey did not stratify by gender, broader research shows women disproportionately shoulder caregiving responsibilities. The national data from Canada's 2018 General Social Survey on Caregiving, found that two-thirds of caregivers of individuals with developmental disabilities are women (19).

FIGURE 55: Almost three-quarters of respondents reported someone in their household had trouble working or keeping a job because their family couldn't get the services or support they needed



RESULTS
FAMILY LIFE

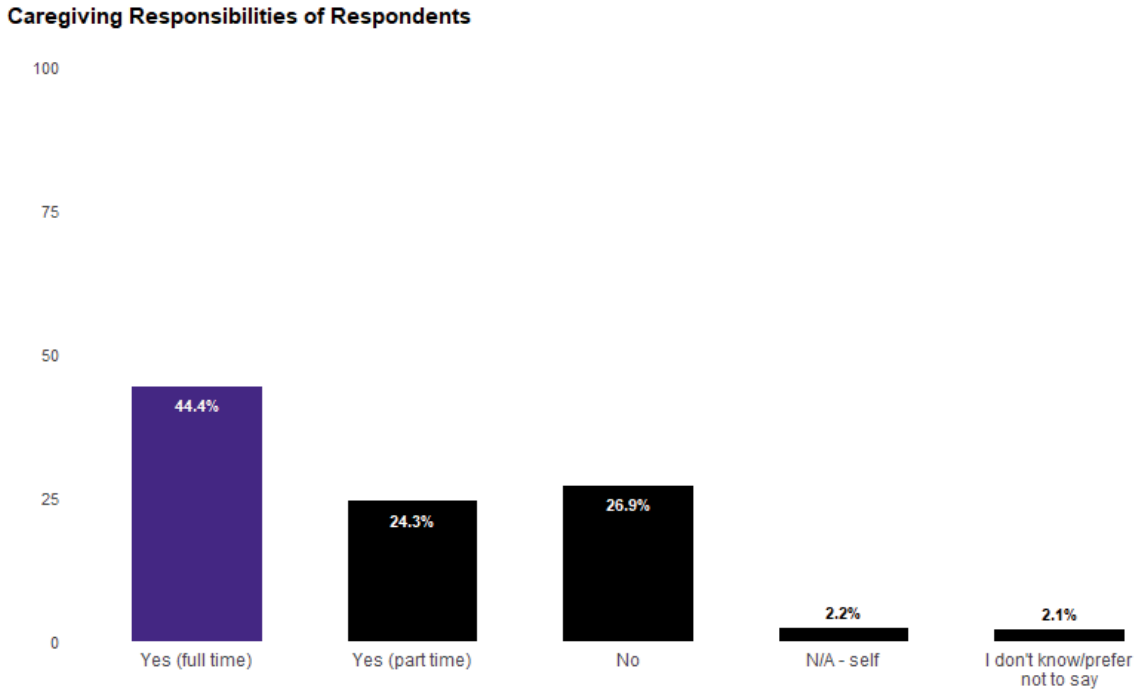
Is someone in your family, like you, your partner, or another relative, staying home full-time/part-time for caregiving purposes?

Respondents who identified as parents/caregivers were asked if they or someone else in their household was staying home full or part-time for caregiving purposes.

These numbers show how many autistic children, youth, and adults in our community have someone in their household providing full-time or part-time care. Among them, 44.4% reported a full-time caregiver, while another 24.3% had a part-time caregiver. Just over a quarter (26.9%) reported not having someone staying at home from work to provide caregiving support. A very small number of respondents either did not know or were completing the survey for themselves (2.1% and 2.2%, respectively), indicating that the vast majority of the sample is receiving caregiving from a family member full/part-time.

The fact that 44.4% of respondents indicated full-time care underscores the intense demands placed on families in this community. For households with family members with complex needs, full-time caregiving often means a significant disruption to employment and personal well-being (6). These families are managing high levels of daily responsibility, which can contribute to stress, burnout, and financial strain. The prevalence of full-time caregiving highlights the broader systemic gaps in supports and services that force families to take on roles that extend far beyond typical parenting responsibilities (18). This reality also exposes the system's heavy reliance on the unpaid labour of parents and caregivers — individuals who are, in effect, holding up the very system that is failing them. Without adequate investment in respite, funding, and coordinated supports, families are left to shoulder the burden of care that rightly belongs within a functioning public system.

FIGURE 56: Almost half of the survey sample has a family member staying home full-time for caregiving responsibilities



RESULTS
COST OF SERVICES

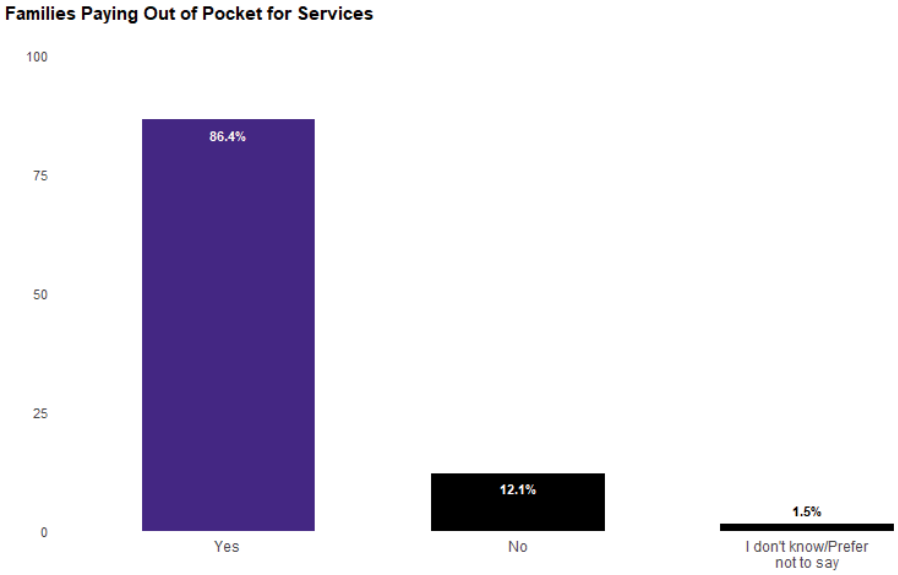
Have you ever paid out of pocket for services?

Respondents were asked if they had ever purchased services out of pocket for the person the survey was about.

An overwhelming 86% of respondents (n=691) reported that they have paid out of pocket for services, while only 12% indicated that they had not. Just 1.5% of respondents were unsure or preferred not to answer.

This finding underscores the extent to which families are bearing the financial burden of care themselves, reflecting deep gaps in publicly funded support systems. The scale of out-of-pocket spending highlights the inequity families face; those with financial means can access services privately, while others go without, leading to widening disparities in outcomes. As shown in recent research, many families report paying thousands of dollars annually out-of-pocket for diagnosis, therapy, and essential supports — with median non-medical costs exceeding four times the annual medical and therapy costs (6). Graziosi, Rodrigues, Tian, Birnbaum and Neil show 39% of caregivers reported going into debt, and many noted they were forced to forgo essential services or take on extra employment simply to meet their child's needs. These findings illustrate a structural inequity: access to autism supports in Ontario is often determined not by clinical need, but by the ability to pay, perpetuating long-term disparities in health, education, and family well-being (6).

FIGURE 57: The majority of the survey sample has had services that were purchased out of pocket



RESULTS
COST OF SERVICES

What services/supports did you pay for? (choose all that apply)

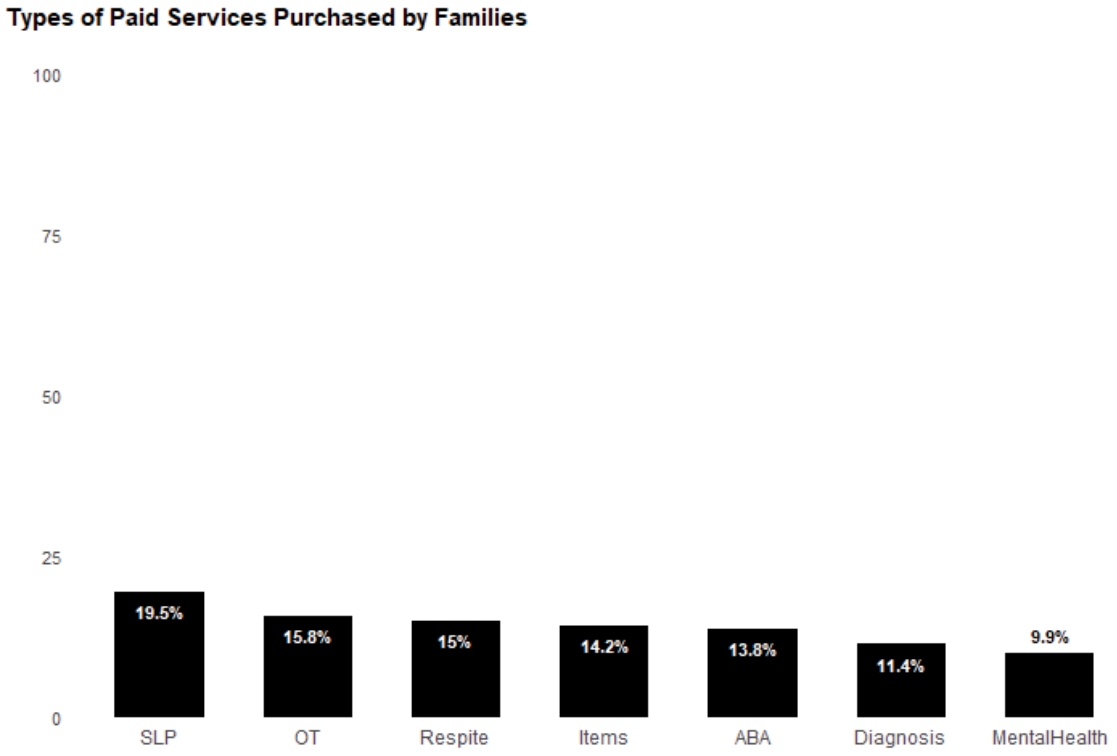
Respondents who indicated purchasing services were asked which they had purchased.

Families reported paying out of pocket for a wide range of services, with the most commonly purchased supports being speech-language pathology (SLP) (19.5%) and occupational therapy (OT) (15.8%). Applied Behaviour Analysis (ABA) (13.8%), respite services (15.0%), and therapeutic or developmental items (14.2%) were also frequently purchased.

Notably, mental health supports were purchased by nearly one in ten families (9.9%), underscoring a significant gap in publicly funded access to these services. Spending on diagnostic assessments (11.4%) reflects persistent barriers to timely diagnosis through the public system. Very few families (too few to report) reported paying for assisted housing-related supports, likely reflecting both the rarity and high cost of such options (as well as a low number of respondents in that stage of life captured by this survey).

Overall, the distribution of out-of-pocket spending highlights that families are shouldering considerable costs for essential therapies and supports that should be accessible through public funding (6). The data suggest that core clinical and developmental services, particularly SLP, OT, and ABA, remain insufficiently available within the Ontario Autism Program and related systems of care.

FIGURE 58: The majority of the survey sample has had services that were purchased out of pocket for them by family



RESULTS
COST OF SERVICES

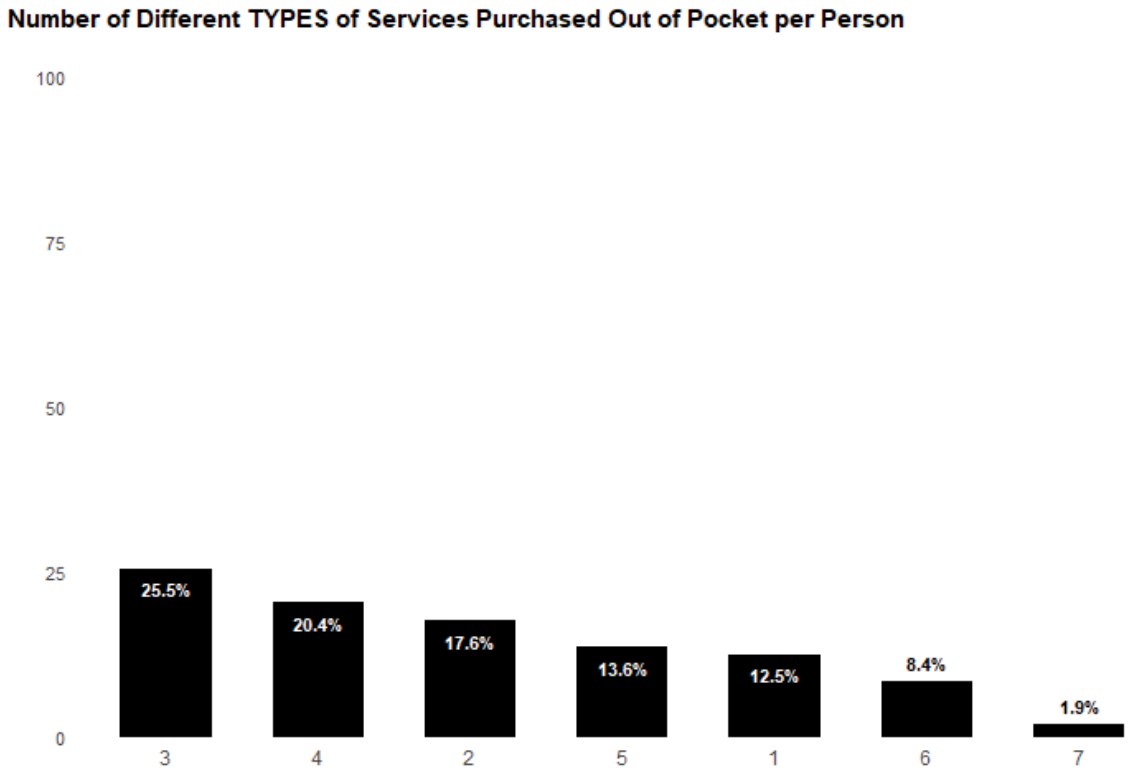
Number of Different Paid Services Purchased per Person

Most families are purchasing multiple types of services out of pocket. Nearly half of respondents (46%) reported paying for three or four different types of services for the individual the survey is about (25.5% for three services, 20.4% for four services).

Smaller proportions of families purchased only one or two services (12.5% and 17.6%, respectively), while a minority purchased five or more services (13.6% for five services, 8.4% for six services, and 1.9% for seven services).

These results highlight that families often need to access multiple supports simultaneously, reflecting the complexity of needs and the gaps in publicly funded services. The high proportion of families managing three or four services out of pocket suggests significant financial and logistical burdens on households navigating therapeutic, diagnostic, and support services.

FIGURE 59: Nearly half of respondents reported paying out of pocket for three or four different types of services for the individual the survey is about



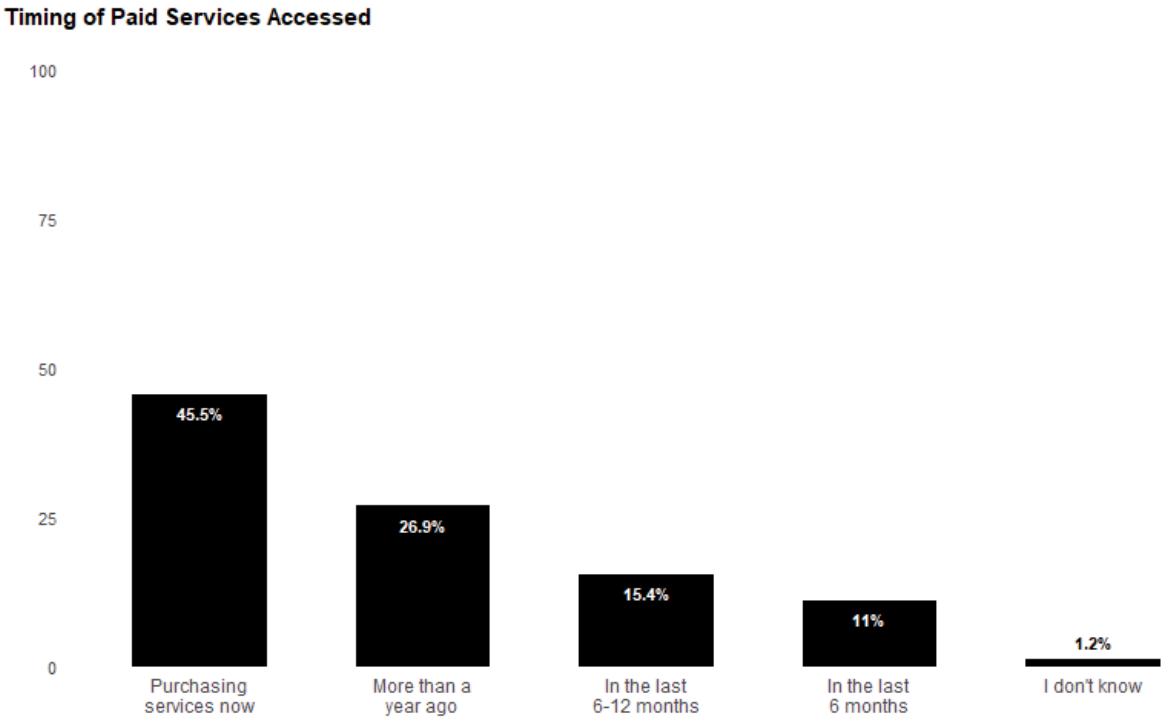
RESULTS
COST OF SERVICES

Timing of Paid Services Accessed by Families

The survey results show that nearly half of families (45.5%) were actively purchasing services for the individual the survey is about. A smaller proportion accessed services more recently, with 11.0% reporting purchases in the last six months and 15.4% in the last 6 to 12 months. Notably, 26.9% of families last purchased services more than a year ago, suggesting either that their needs were met previously or that there are gaps in ongoing access to supports. Very few respondents (1.2%) reported not remembering when services were purchased.

Overall, these findings indicate that a substantial portion of families are continuing to invest significant personal funds to secure essential services that are not consistently available through publicly funded programs. This aligns with recent research showing that families of autistic children in Ontario face high out-of-pocket expenses for diagnosis, therapy, and day-to-day supports, with median non-medical costs exceeding four times annual therapy costs and nearly 40% of families incurring debt to afford care (6). Together, these findings highlight both the financial and logistical burdens families face and the inequities created when access to critical supports depends on the ability to pay rather than clinical need.

FIGURE 60: Nearly half of respondents reported paying out of pocket for services at the time of the survey



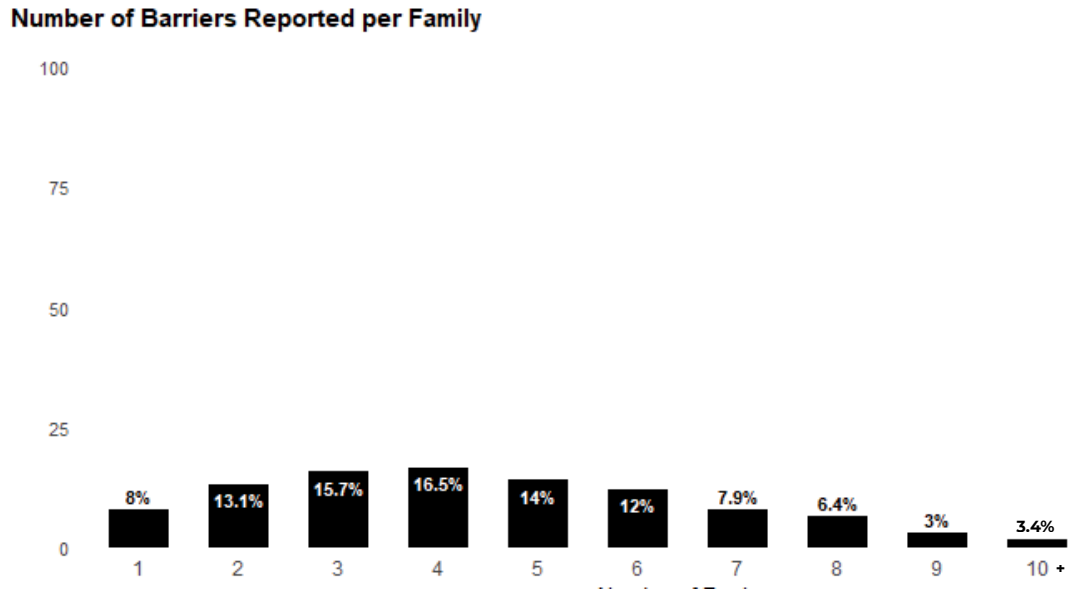
RESULTS
BARRIERS

Respondents were asked about barriers to services:

Respondents reported experiencing a wide range of barriers when trying to access services, with some challenges affecting a substantial number of respondents. The most commonly reported issues, aside from waitlists, included insufficient funds, long waitlists at local providers, difficulty supplementing funds, and parent or caregiver mental health. Other notable barriers were a lack of relevant local service providers, distance to service providers, and the complexity of Core Clinical Services funding management. Less frequently reported challenges included language barriers, lack of culturally appropriate services, unreliable computer or internet access, and being caught in an AccessOAP appeals process. Overall, these findings indicate that financial and structural barriers remain the most significant obstacles for families, while system navigation and technical challenges, though less common, continue to affect many.

Families reported experiencing multiple barriers when accessing services, with many facing more than one challenge simultaneously. Only a small proportion of families (8%) reported experiencing just one barrier. The largest groups faced four barriers (16%), three barriers (16%), or five barriers (14%), indicating that multiple challenges are common. A significant number of families reported experiencing six barriers (12%) or two barriers (13%). Fewer families reported experiencing seven or more barriers, with only 3–8% of families falling into these higher categories. These findings highlight that most families encounter several overlapping barriers, reinforcing the cumulative impact of structural, financial, and system-level challenges on their ability to access supports effectively.

FIGURE 61: Most respondents reported experiencing more than one type of barrier while trying to access services



RESULTS
BARRIERS

In an open-ended question about barriers experienced, respondents described a wide range of challenges in accessing services, highlighting both systemic and practical barriers. Common themes included long waitlists for funding and services, lack of flexibility or coverage in the Ontario Autism Program (OAP), financial strain from paying out-of-pocket, difficulties navigating complex administrative processes, limited local service availability, and insufficient supports for older children or adults. Several parents also emphasized the emotional toll and exhaustion caused by trying to coordinate multiple services while managing work, caregiving, and other life responsibilities. These responses illustrate how the cumulative impact of barriers extends beyond service access to affect overall family wellbeing.

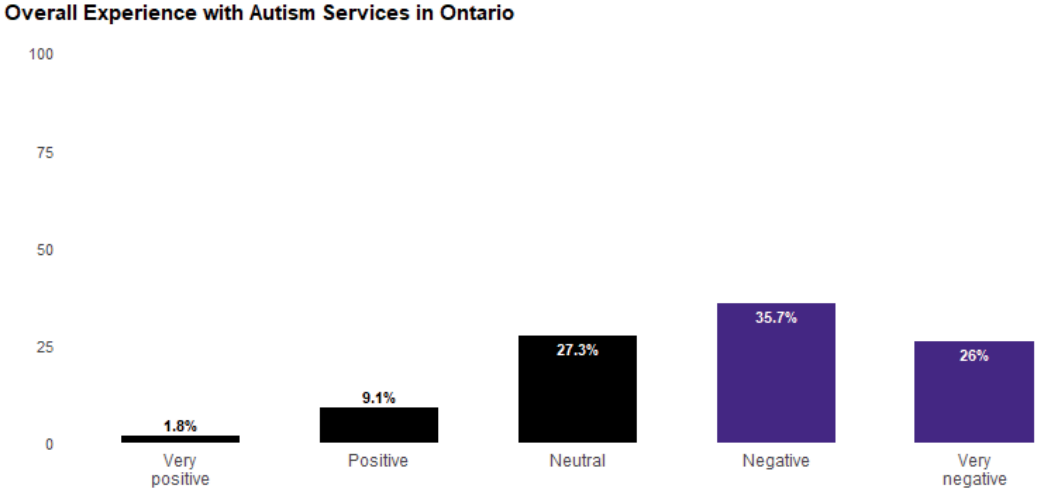
RESULTS
OVERALL

Overall, how would you rate your experience with autism services in Ontario?

All families were asked about their overall experience with autism services in Ontario.

Families' overall experiences with autism services were largely negative, with the majority reporting dissatisfaction. Over one-third of respondents described their experience as negative, and an additional quarter described it as very negative, highlighting widespread frustration with the system. About a quarter of families were neutral, indicating that services may meet some needs but often fall short. Only a small proportion of families reported positive or very positive experiences, suggesting that while some families do find support helpful, these cases are relatively rare. These findings underscore the urgent need for improvements in accessibility, funding, and service quality to better support families.

FIGURE 62: Most respondents reported a negative experience with services in Ontario



RESULTS
OVERALL

Is there anything else you would like to share about your experience with any of the autism services currently offered in Ontario?

Families across Ontario are facing an unbearable struggle navigating autism services. Parents are forced to shoulder the immense financial burden of private therapies, often selling homes, quitting jobs, or reducing work hours just to ensure their children receive care. Early intervention, a critical window for children, is frequently delayed by waitlists stretching five years, meaning children miss out on critical support. Schools often lack the training and resources to support high-needs or non-verbal children, leaving parents to coordinate care at home with little guidance. Rural families face even greater barriers, with limited access to qualified professionals and respite supports. Caregivers report exhaustion, depression, and burnout; mental health services for families are minimal or inaccessible. Programs designed to help, such as the Ontario Autism Program (OAP), are hampered by age caps, bureaucratic complexity, and poor communication, leaving families feeling isolated and unsupported. Despite the dedication of service providers, the system's structural failings, like long waitlists, inequitable access, and needs ignored in favour of arbitrary age limits, have caused profound stress, financial strain, and lost developmental opportunities for children. Families are advocating not for luxury, but for a system that allows their children to thrive, with timely, needs-based support, accessible early intervention, and meaningful caregiver assistance.

RESULTS
OVERALL

Summary of Parent and Caregiver Experiences with Ontario Autism Services

1. Financial Burden and Out-of-Pocket Costs
- Families are forced to pay tens of thousands of dollars for therapies due to long waitlists for publicly funded programs.
- Some families have sold homes, quit jobs, or reduced work hours to afford necessary therapies.
- Funding inconsistencies and delayed access (5 years) mean that children often miss critical early intervention years.
- Programs like SSAH are inadequate; reimbursement processes add additional financial strain, particularly for families who must pay upfront.

2. Impact of Waitlists on Early Intervention and Development
- OAP funding and core clinical services are only accessible years after diagnoses, after critical developmental periods.
- Long waits for ABA, SLP, OT, and other therapies result in lost developmental opportunities.
- Age caps on services exacerbate inequities; children often age out before receiving necessary support.

3. Systemic Navigation Challenges
- The OAP and related programs are bureaucratically complex, creating a heavy mental load for families.
- Families lack clarity on application status, waitlist timelines, and eligibility.
- Parents report feeling isolated, unsupported, and responsible for coordinating all aspects of care.

4. Inadequate Support in Schools and Communities
- Schools often lack resources or knowledge to support children with autism, especially non-verbal or high-needs students.
- Home-based consultative strategies place additional stress on parents.
- Northern, rural and remote communities face severe gaps in service availability and access.
- Limited availability of qualified professionals, respite workers, and bilingual supports further restricts access.

5. Mental Health and Caregiver Well-Being
- Parents report high levels of stress, anxiety, and depression, with some experiencing mental health crises due to systemic failures.
- Caregivers often leave the workforce to provide necessary care, compounding financial and emotional strain.
- Mental health support for caregivers is insufficient and difficult to access.

6. Inadequate Program Design and Regulation
- Core clinical services are not needs-based and are constrained by arbitrary age limits.
- Lack of transparency about private eligible providers leads to inconsistent access, unethical billing practices, and inequitable service distribution.
- Cross-ministry collaboration (Health, Education, CAS) is minimal, resulting in fragmented and inefficient service delivery.

RESULTS
OVERALL - IN OUR OWN WORDS

Financial strain/sacrifices:

- “We knew it would be years before we got access to funding through the OAP, so we sold our home and moved an hour away. I now have a huge commute because I can’t find a job close to home… We are now using the money from the equity in our home to pay for our son’s therapy.”
- “Autism services are just not affordable for the average family without funding. We've gone 5 years just choosing not to give him therapies he needs because we can't afford it… Just imagine how much he's missed out on because of this.”
- “We are drowning financially, only one parent can work… Even though we have SSAH funding, we cannot access it as we are unable to pay upfront and wait 1-2 months to be reimbursed.”

Waitlists / delayed access / early intervention:

- “The wait list is so long you don’t get an opportunity to have early intervention and services. My son was diagnosed at 2 and still passed the early years stage when we got funding—it’s ridiculous.”
- “Early intervention is key! My daughter is now almost 8 years old and non-verbal with no help.”
- “Waitlists are insane, and by the time you get any funding to actually help your child they are over 10 at that point when so many things are crucial for learning under 5.”

Systemic/administrative frustrations:

- “Navigating autism services in Ontario is one of the most traumatic experiences of our family’s life. Barrier after barrier, dehumanizing experience after dehumanizing experience.”
- “I do not understand why we need a DON every year if we are ok with receiving the minimal amount. Why spend money on useless meetings?”
- “Families and caregivers like me feel lost and overwhelmed. The portal is not user-friendly and it is near impossible to keep track of what is being said.”

Impact on mental health/caregiver strain:

- “I am confused all the time. I don’t know what the right thing to do for my child is… it is costing me thousands of dollars to just keep our child in school and alive.”
- “The strain of caring for two autistic children forced me to give up my hard-won career. I have not earned an income in 15 years.”
- “Absolutely soul crushing. Complicated, too administrative-heavy, burden on families is unnecessary.”

Equity/fairness / human rights:

- “Why should a family have to financially ruin themselves so a member can get the therapy they need?… I think it is disgusting and a human rights violation that my child does not receive government funding under our health care program.”
- “Autistic kids wait years for services, and they are horrifyingly under-supported in schools, being cared for by incredibly overwhelmed caregivers.”
- “There needs to be better regulation of prices places can charge for services. Age caps in a program that has a 5-7 year wait is just cruel. It’s heartless and it needs to change.”

DISCUSSION

DEMOGRAPHICS

The 2025 OAC Community Survey received responses from a broad cross-section of families across Ontario, representing urban, suburban, rural, and northern regions. The overwhelming majority of respondents identified as parents or primary caregivers of autistic children and youth under 18. This provides a comprehensive snapshot of family experience within the Ontario Autism Program (OAP) and related systems.

Regional distribution was fairly balanced, though participation was highest in Southern and Central Ontario. Families in rural and northern regions consistently reported greater difficulty accessing diagnostic, therapeutic, and respite services. The survey also revealed the significant economic toll of caregiving: nearly half of households had at least one adult who left the workforce or reduced employment to provide full-time care. This underscores the structural dependency of Ontario's autism service model on unpaid family labour, with far-reaching implications for economic security and gender equity (6, 19).

DIAGNOSIS

Families continue to experience long waits for autism diagnosis, with most children diagnosed between the ages of four and nine, well beyond the optimal window for early intervention. Late diagnosis delays registration in the OAP and subsequent access to early supports, cascading into service delays throughout a child's development.

Many respondents reported turning to private assessments, often at considerable personal cost, because of wait times in the public system. Families in northern and rural areas reported waits of over two years. This pattern reflects a systemic inequity in access to diagnostic resources across regions. The data reinforce the need for consistent early screening, publicly funded diagnostic capacity, and coordinated referral pathways.

ONTARIO AUTISM PROGRAM (OAP) ACCESS

Access to the OAP remains inconsistent, opaque, and heavily bureaucratized. Less than one-third of children in the survey were accessing any OAP services at the time of the survey. Families described a complex registration process with limited guidance, eligibility criteria that are difficult to meet, and poor communication from the Ministry.

A recurring theme is the absence of transparency: families do not know where they stand in the queue, how long they will wait, or what services will be available when funding is received. Some reported relocating to access supports, while others described disengaging from the process entirely. These findings reveal a systemic gap between policy intent and implementation, where administrative complexity undermines access to essential care.

DISCUSSION

ENTRY TO SCHOOL (ETS)

Among the subset of families who accessed the Entry to School (ETS) pillar program, satisfaction levels were generally high. Approximately two-thirds of participants rated ETS positively, citing strong support from staff and visible gains in communication, social, and adaptive skills.

However, access to ETS remains limited: only about one-quarter of eligible children have participated, and wait times of up to six months are common. Half-day schedules and transportation barriers limit participation, particularly for working families. Parents also noted a lack of post-program follow-up or coordination with schools, leading to discontinuity between ETS and the classroom environment. While ETS is one of the OAP's better-regarded components, its impact is constrained by scale and lack of continuity.

URGENT REPONSE SERVICES (URS)

The Urgent Response Services pillar program was designed to address acute crises and prevent escalation, yet the program is not functioning as intended. Only 23 percent of families accessed URS, and of those, nearly half reported dissatisfaction. Respondents cited restrictive eligibility criteria, prolonged intake processes, and limited service duration, typically capped at 12 weeks, as major limitations.

Families frequently reported being told that their circumstances were "not urgent enough," despite facing school exclusions, mental health crises, or safety concerns. The findings suggest that URS has become reactive rather than preventative, serving a narrow segment of families instead of addressing the broader need for timely stabilization and transition to ongoing supports.

FOUNDATIONAL FAMILY SERVICES (FFS)

The Foundational Family Services (FFS) pillar programs are intended to be universally accessible, yet only 37 percent of families in the survey reported having used them. The most common reasons for non-participation were lack of awareness and regional unavailability. Families who accessed FFS described them as overly generic, primarily consisting of parent-led webinars or information sessions.

While some families found value in group learning opportunities, many reported that FFS did not address their child's individualized needs. Families expressed frustration with being expected to take on therapeutic roles without adequate professional support. Burnout, rather than empowerment, was the prevailing sentiment. FFS, while conceptually sound, requires significant reform to align with its intended goal of empowering families through accessible and meaningful supports.

DISCUSSION

CAREGIVER-MEDIATED EARLY YEARS (CMEY)

Participation in the Caregiver-Mediated Early Years (CMEY) pillar program remains low, with only one in five families reporting access. A substantial portion of families were ineligible because their children aged out while waiting, while others cited program unavailability in their region.

Families who participated generally appreciated the structured guidance but raised concerns about the short duration (typically eight to twelve weeks) and rigid scheduling. Many described CMEY as “too little, too late.” Although satisfaction rates were moderately high among participants, families emphasized that the short-term, parent-led format places excessive demands on caregivers already managing multiple responsibilities. The model’s scalability appears to have come at the expense of accessibility and depth of support.

CORE CLINICAL SERVICES (CCS)

Core Clinical Services (CCS) are the cornerstone of the OAP, yet they remain the most inaccessible component. Among 906 children reported registered to the OAP, in the survey, only 224 were actively receiving CCS funding, a mere one-quarter of eligible participants. The average age of children accessing CCS was 13.5 years.

Families reported widespread dissatisfaction with both the timeliness and adequacy of CCS funding. Nearly half indicated that their allocations were insufficient to meet assessed clinical needs, and many struggled to find providers within their budgets. Administrative barriers such as complex reconciliation requirements and funding gaps between renewals exacerbate family stress. The data indicate that CCS, in its current form, is neither timely nor equitable and is failing to deliver on its foundational purpose.

Interestingly, the roughly 25% of families in our sample who expressed dissatisfaction (13% “Dissatisfied” + 12% “Very dissatisfied”) mirrors, by rough approximation, estimates from U.S. autism surveillance data that about 26.7% of autistic children fall into the “profound autism” category (20). While our measure is about perceptions of funding, and theirs is about clinical severity, the similarity in proportions is compelling: it suggests that the portion of families dissatisfied may overlap substantially with those caring for children with the highest support needs. Anecdotally, the OAC hears from these families frequently, and this is, in fact, one of their more common issues, CCS funding doesn’t come close to meeting their child/youth’s clinical needs.

APPLIED BEHAVIOURAL SERVICES (ABA)

Applied Behavioural Analysis remains the most commonly accessed therapy among families in the survey. However, affordability and service intensity are declining. Nearly three-quarters of families reported that the cost of ABA increased over the past year, while more than half had to reduce therapy hours as a result.

This trend reflects a broader erosion of purchasing power as CCS funding levels remain static amid inflation. Families describe making difficult trade-offs; cutting back on therapy hours, pausing services, or taking on debt. The survey results highlight the inadequacy of current funding levels and the need for regular indexation to ensure that families can maintain consistent therapeutic intensity over time.

DISCUSSION

DETERMINATION OF NEEDS (DON) PROCESS & APPEAL

The Determination of Needs (DON) process was intended to allocate funding based on individual assessment, but the data reveal significant flaws. Of families who received CCS funding, about ten percent pursued an appeal of their DON decision. Nearly one-third of these appeals took more than seven months to resolve, and 62 percent of families were dissatisfied with the outcome.

Families described the DON process as opaque, inconsistent, and emotionally taxing. Long appeal timelines reduce the effective funding period and erode trust in the system. The findings suggest that the DON mechanism, as currently implemented, introduces inequity and administrative friction without achieving its intended goal of fairness and transparency.

ADULT SERVICES

Although adult respondents were a small subset of the total sample, their responses highlight critical service gaps in Ontario's transition from child to adult supports. Few adults reported accessing developmental services or housing supports, and most relied solely on Passport funding or the Ontario Disability Support Program (ODSP). Waitlists for day programs and mental health care were common.

Families expressed concern about the "service cliff" that occurs when youth age out of the OAP, often resulting in isolation and loss of structure. The lack of continuity between child and adult services leaves families to navigate a fragmented landscape with little guidance or support. This systemic gap underscores the need for a coordinated lifespan approach to autism services.

RESPITE

Respite services are in high demand but chronically underprovided. The survey found that nearly 44 percent of families are on waitlists, and only 17 percent of those receiving respite reported that it adequately met their needs. Wait times of one to four years are common, and families frequently rely on multiple sources, such as SSAH, private respite, or informal care, to patch together support.

Insufficient respite contributes to caregiver burnout and family breakdown. Families consistently identify respite as one of the most essential yet neglected aspects of the support system. The findings make clear that respite should be treated not as a supplementary service but as a main component of family well-being and sustainability.

DISCUSSION

SCHOOL

School participation data reveal persistent exclusion and under-support of autistic students. While most children attend public schools, nearly half of families reported that their child does not receive the accommodations they require. Approximately nine percent are not enrolled in school at all due to a lack of appropriate support, and a further six percent experience frequent suspensions or exclusions.

Families describe being called to pick up their children mid-day, having schedules reduced to part-time, or withdrawing altogether. These experiences point to systemic underfunding of special education, insufficient staff training, and inconsistent application of inclusive education principles across boards. The gap between educational policy and classroom practice remains significant (14, 15, 16, 17).

CHILDRENS' AID SOCIETY

A striking and deeply concerning finding is that nearly one in six families considered contacting the Children's Aid Society (CAS) for help because of service gaps, and almost nine percent actually did. These cases were not about protection concerns but desperation for assistance.

This trend signals a systemic failure where the lack of autism services drives families into the child welfare system. It underscores the need for coordinated cross-ministerial accountability to prevent children from entering care due to service inadequacy rather than safety issues.

This pathway should not exist.

MENTAL HEALTH

Survey responses reveal that mental health challenges among autistic individuals and their families remain a pervasive and unaddressed crisis across Ontario. Families consistently described high levels of stress, burnout, and emotional exhaustion, often compounded by long waitlists, lack of specialized providers, and limited access to affordable, autism-informed care.

The findings underscore that mental health cannot be treated as separate from broader systemic failures in the Ontario Autism Program, education, and respite systems. When children and caregivers cannot access timely supports, mild distress escalates into acute mental health crises, crises that are then met with emergency interventions rather than prevention or continuity of care. Respondents emphasized the need for a provincial strategy that integrates autism and mental health services, invests in qualified professionals, and provides ongoing, accessible supports across the lifespan. Without this integration, families will continue to experience preventable suffering, and Ontario will fail to meet even the most basic standards of care for autistic individuals.

DISCUSSION

FAMILY LIFE

The cumulative impact of inadequate services is profound. Families report chronic stress, financial strain, and emotional exhaustion. Nearly half have one caregiver staying home full-time due to a lack of suitable programs or school inclusion. The burden of coordination, navigating multiple waitlists, appeals, and paperwork, exacerbates burnout.

These findings illustrate how system fragmentation translates into human cost. Families are functioning as case managers, educators, and therapists in addition to their caregiving roles (13, 18). The data demonstrate that without systemic reform, the OAP will continue to depend on unpaid and unsustainable family labour.

COST OF SERVICES

Financial pressures are a defining feature of family experience. Rising costs of therapy, travel, and private assessments, combined with stagnant OAP funding, mean that families are purchasing less service each year (or paying more out of pocket). Many report accumulating debt or taking second jobs to sustain supports (6).

The erosion of affordability undermines equity: families with fewer financial resources simply go without. These results underscore the importance of indexing all funding allocations to current therapeutic costs, inflation and regional cost-of-living to preserve access over time.

BARRIERS

The most frequently reported barriers across all service areas are long wait times, regional inequities, complex administrative processes, and insufficient information. Families in Northern and rural Ontario face additional logistical and financial barriers due to distance from providers.

These data demonstrate that systemic design, not lack of demand, is the primary obstacle to equitable service access. Families are not disengaged; they are overwhelmed by a system that is administratively dense and operationally inconsistent.

DISCUSSION

OVERALL

These results depict a fragmented and inequitable system that continues to fail families at every stage, from diagnosis through adulthood. Each program component functions in isolation, creating service discontinuities and administrative burdens. Funding levels and eligibility structures remain misaligned with clinical need.

The overarching narrative is one of resilience amid systemic dysfunction. Families continue to advocate, adapt, and self-fund to fill service gaps. However, the cumulative toll, emotional, financial, and social, is unsustainable. The findings call for a fundamental reinvestment of Ontario's autism services to reflect the lifelong and multidimensional nature of autism.

IN OUR OWN WORDS

Qualitative responses reinforce the statistical findings with personal accounts of exhaustion, frustration, and loss. Families describe feeling invisible within a system that is supposed to serve them. Many express that they are "on their own" despite being registered in government programs.

Parents consistently voice a desire for collaboration, transparency, and respect. Their experiences highlight that behind every data point is a family navigating immense complexity. The message is clear: policy must be informed by lived experience, not designed around administrative convenience.

CONCLUSION
WHAT DOES THIS SHOW

The 2025 Ontario Autism Coalition Community Survey offers a comprehensive, data-driven view of family experiences within Ontario's autism services landscape. Across all domains, diagnosis, education, mental health, respite, and the Ontario Autism Program (OAP), the results reveal systemic inconsistencies, prolonged wait times, and widespread inequities. The findings reinforce what families have long expressed: that the structure of Ontario's autism system is reactive, fragmented, and administratively heavy, leaving families to bear the weight of coordination and cost.

A recurring theme throughout the report is misalignment between program design and family realities, between government communications and lived experience, and between the intent of "family-centred care" and the actual delivery of services. While individual service providers are often described as compassionate and competent, families consistently report that system design impedes access, continuity, and effectiveness.

The current OAP architecture reflects a program that isn't designed to manage volume or to meet need. Age-based funding tiers, short-duration interventions, and narrow eligibility definitions fragment the developmental continuum and undermine outcomes. Early intervention windows are missed; services end abruptly at arbitrary age thresholds; and caregivers, already exhausted, are expected to deliver therapy, coordinate multiple providers, and navigate opaque administrative systems.

Equity gaps are particularly evident across geography and income. Families in Northern and rural regions face disproportionate travel costs, limited provider availability, and longer wait times. Those with higher incomes are more likely to purchase private assessments or therapies, while lower-income families remain dependent on underfunded public streams. This bifurcation entrenches inequality, creating a two-tiered system that contradicts the principles of universality and fairness.

The findings also highlight how systemic inadequacies intersect. Inadequate respite fuels caregiver burnout, which in turn reduces families' capacity to sustain therapeutic programs. School exclusions push children out of educational spaces, leading to crises that overwhelm mental health and emergency systems. Some families, desperate for support, turn to the Children's Aid Society because the service system has failed to respond. These outcomes are not isolated; they are the predictable result of policy fragmentation and chronic underinvestment.

CONCLUSION
WHAT DOES THIS SHOW

Families are not asking for charity; they are asking for competence, coordination, and accountability. The data in this report should be understood as both evidence and testimony: a record of systemic failure, but also of enduring resilience. The OAC community continues to demonstrate extraordinary adaptability and advocacy in the face of structural barriers that no family should have to navigate alone.

To honour that resilience, Ontario's autism policy must evolve from a reactive, program-by-program model toward a coherent, lifespan system of care. This requires investment not only in funding but in shared governance, transparency, and trust. This system was not built "by the community, for the community". The community could see the flaws from the outset, and have been repeatedly ignored when bringing them forward to the decision makers. Change must be guided by evidence, actually co-designed with autistic individuals and families, and evaluated against outcomes that reflect real-world progress, not administrative targets.

These survey results make the path forward clear: the province must move beyond incremental change and toward a comprehensive, truly needs-based, and accountable autism strategy. Only then will Ontario begin to rebuild confidence among families who have waited far too long for a system that sees them, hears them, and meets their needs.

RECOMMENDATIONS
POLICY, FUNDING, TRANSPARENCY

Diagnosis and Early Identification

Ontario must prioritize early identification and diagnosis as the foundation of equitable access to autism services. Universal screening protocols and consistent referral pathways should be embedded within primary care, early childhood education, and public health systems. Publicly funded diagnostic capacity must be expanded to eliminate multi-year wait times that delay access to the Ontario Autism Program (OAP). Diagnostic teams should reflect Ontario's geographic diversity, ensuring that families in rural and northern communities have equitable access through regional hubs or telehealth options. In these areas, teams need to be bolstered with sustainable increases in trained staff. Transparent, province-wide data on diagnostic wait times should be published annually by the Ministry of Children, Community and Social Services (MCCSS), to support accountability and policy planning.

Ontario Autism Program (OAP) Access and Navigation

Families require a system that is accessible, transparent, navigable, and equitable. The Ministry of Children, Community and Social Services (MCCSS) should provide families with individualized case navigation and clear communication about their position on the waitlist, expected timelines, and available interim supports (on an ongoing basis). The OAP registration process should be simplified to reduce administrative burden, and all program documentation should be accessible in plain language and multiple formats. Families should never have to "guess" where they are in the process of accessing a service. A transparent and coordinated intake process is essential to rebuild trust and reduce attrition from the program. OAP access statistics, such as OAP registrations, should be made available publicly once again by MCCSS, on a monthly basis.

Entry to School (ETS)

The Entry to School program has shown positive outcomes for participating families, but its reach and continuity must be strengthened. The program should be expanded to full-day and school-embedded models that better meet the needs of working families and children requiring more intensive transition supports. By moving this program to management under the Ministry of Education, coordination between ETS providers and local school boards would be stabilized. Formalized relationships would ensure that gains made in the program carry over into classroom environments. Post-program follow-up services should be funded via the Ministry of Education to support ongoing skill generalization and stability during the critical early school years.

RECOMMENDATIONS
POLICY, FUNDING, TRANSPARENCY

Urgent Response Services (URS)

Urgent Response Services require a thorough reassessment. The program's return on investment is increasingly in question, and both families and service providers are raising serious ethical concerns about its design, purpose, and overall effectiveness. If URS is intended to function as a genuine crisis stabilization program rather than a narrowly defined short-term intervention, several fundamental changes would be required: eligibility criteria must expand to include moderate crises and school-based behavioural challenges; service duration must extend beyond twelve weeks when clinically indicated; and structured follow-up supports must be mandatory to prevent families from falling back into crisis. Yet, if URS were to operate with this broader scope, its current costs would more closely align with those of the Children's Community Support (CCS) program, raising critical questions about duplication, efficiency, and the best use of limited public resources.

Foundational Family Services (FFS)

Foundational Family Services should be redesigned by providers to fulfill their intended role as accessible, preventative, and empowering supports for all families. This requires a shift from generic, webinar-style delivery toward individualized, skills-based programs that address family-specific goals. FFS should include repeatable, tiered supports that families can reaccess as their child's needs evolve. Regional service equity must be monitored through transparent public reporting. To achieve meaningful impact, MCCSS should fund family coaching, peer mentoring, and community-based programming that directly reduces caregiver stress and isolation.

Caregiver-Mediated Early Years (CMEY)

The CMEY program must be strengthened to ensure consistent access and lasting impact. Eligibility should be expanded to include children who age out while waiting for placement, and flexibility should be built into scheduling to accommodate working caregivers. Program duration should be extended to provide sufficient time for learning, practice, and follow-up. Hybrid delivery models that combine in-person and virtual components can improve accessibility without sacrificing quality. The Ministry should also establish quality assurance mechanisms to ensure consistency across service providers and accountability for outcomes.

RECOMMENDATIONS
POLICY, FUNDING, TRANSPARENCY

Core Clinical Services (CCS)

Meaningful investment in Core Clinical Services is critical to restoring the integrity and credibility of the Ontario Autism Program (OAP). According to the Ministry itself, the program was designed to support only 20,000 children and youth in Core Clinical Services (CCS) at any one time, a figure that falls dramatically short of need (21). The 2024 Ontario Budget reaffirmed this limited scope, stating that the government's additional $120 million investment would "support the government's commitment to enrol 20,000 children and youth in core clinical services" (21). Yet as of August 6, 2025, there are 84,405 children and youth registered for the OAP. This means that roughly three-quarters of eligible children remain waitlisted for years without access to the very supports the program was designed to deliver.

The gap between design and demand is now untenable. The OAP must be urgently scaled up to meet the real prevalence of autism in Ontario, currently estimated at 1 in 38 children, and to reflect the government's responsibility to provide equitable, needs-based services to every child who qualifies. Anything less risks deepening inequities and further eroding public trust in a system already stretched beyond its limits.

Age-based funding caps should be eliminated and replaced with funding allocations grounded in individualized clinical assessment and actual need. Wait times must be reduced through increased intake capacity, workforce development, and regional service expansion to ensure equitable access across Ontario.

Administrative processes, including the annual Determination of Needs (DON), must be simplified and less frequent. Families should have direct access to their DON results, and the Ministry should publish key performance indicators such as average wait times to funding access, funding levels, and service utilization. Transparent reporting will allow families to understand where they stand and plan for the future with clarity and confidence.

Funding levels must be indexed to annual therapeutic costs and inflation to prevent the erosion of service intensity over time. Provider accountability should be strengthened through requirements for transparent service plans, pricing, measurable outcomes, and adherence to ethical practice standards. A list of OAP eligible providers should be made available on the AccessOAP dashboard and available to families BEFORE they start shopping.

Core Clinical Services must also be better integrated with mental health and education systems to ensure continuity of care and avoid duplication or service gaps. Transition planning is essential to prevent service interruptions as children grow and their needs evolve. Finally, the program must embed family partnership and feedback loops at every stage, from policy design to implementation, to ensure that services remain responsive, effective, and grounded in the lived experience of the community.

Applied Behavioural Analysis (ABA)

To preserve access to evidence-based therapy, the province should implement a mechanism for annual inflation indexing of OAP funding allocations. Service providers should be required to report rate structures transparently, and the Ministry should monitor cost trends to prevent price inflation that undermines access. Support for professional development and workforce retention in the ABA field will be essential to sustaining service capacity.

RECOMMENDATIONS
POLICY, FUNDING, TRANSPARENCY

Determination of Needs (DON) and Appeals

The Determination of Needs process must be restructured for fairness, efficiency, and transparency. Appeals should be resolved within a 60-day standard to ensure timely funding adjustments. The DON tool itself should be subject to external review to evaluate its validity, reliability, and potential bias. The tool should be publicly available to families. Families must have access to clear explanations of their assessments and the rationale behind funding decisions. The appeals process should be simplified and accompanied by direct support for families navigating complex documentation. Transparent publication of aggregate DON outcomes would improve system accountability and public confidence.

Respite Services

Respite must be recognized as a key component of family well-being, not treated as an optional add-on. The province should guarantee baseline access to respite for all autistic people and their families, regardless of income or geography. Waitlists should be publicly reported, and service levels standardized across regions. Flexible respite models, including in-home, community-based, and overnight options, should be expanded to reflect diverse family needs. Funding must allow for the choice of provider and continuity over time. Adequate respite provision is central to preventing caregiver burnout and family breakdown and should be integrated into every level of service planning. Funding should be direct and not reimbursement, which currently limits those without immediate access to funds from receiving the help they need. Furthermore, respite should be adequately funded through dedicated programs outside of the OAP to preserve the clinical integrity and intended purpose of the province's only program offering clinical supports. Establishing a separate, adequately funded and sustainable funding stream for respite would ensure that therapeutic and clinical resources remain focused on treatment and developmental outcomes, while families receive the essential relief required to maintain stability, well-being, and long-term caregiving capacity.

Education and School Inclusion

Ontario's education system must be held accountable for inclusive practices and equitable access for autistic students. The Ministry of Education should establish province-wide standards to prevent informal exclusions and ensure transparent reporting of part-time placements, suspensions, and modified schedules involving students with disabilities. Additional investment in Educational Assistant (EA) staffing, training, and autism-informed classroom practices is required to meet student needs safely and effectively. Coordination between the OAP and school boards should be formalized to align therapeutic goals and educational supports. Education must become a pillar of inclusion, not a site of exclusion.

The findings of the OAC Special Education Survey (2023–2024) make clear that systemic underfunding, staff shortages, and inconsistent accountability mechanisms are undermining the right to a meaningful education. Nearly half of families reported dissatisfaction with IEP implementation, personal support, and safety at school. To address these gaps, the province should establish provincial consistency in IEP standards, mandate public reporting on exclusion and seclusion/restraint data, and ensure adequate funding for classroom safety and support ratios. Schools should be required to maintain annual inclusion action plans, with clear metrics for accessibility, staff training, and family consultation. Finally, the government should convene a Special Education Task Force, including families, educators, unions, and advocacy organizations, to reform policy and funding models to reflect the principles of inclusion (with proper accommodations), transparency, and accountability.

RECOMMENDATIONS
POLICY, FUNDING, TRANSPARENCY

Adult Services and Transitions

The transition from child to adult services represents one of the most significant systemic gaps. The province should establish a formal transition pathway beginning at age 16 to ensure continuity of supports. Adult developmental services, housing, and employment programs must be greatly expanded to meet growing demand. Funding envelopes should allow for individualized planning and meaningful day programming that fosters independence, community participation, and quality of life. Coordination between the OAP and adult funding should be seamless, preventing the “service cliff” that families currently experience.

Mental Health and Family Well-Being

Autism-informed mental health services must be embedded across all levels of care. The province should develop a specialized stream of publicly funded mental health supports for autistic children, youth, and adults, delivered by clinicians with dual training in developmental and mental health disciplines. Caregiver mental health supports should be integrated into OAP navigation services. Cross-sector collaboration between MCCSS and the Ministry of Health is essential to reduce duplication and ensure continuity between therapeutic, behavioural, and psychiatric care. Preventative mental health intervention should replace crisis-driven service delivery.

Cost of Services and Equity

To ensure sustainability and fairness, all OAP funding must be indexed to annual therapeutic costs, inflation and adjusted for regional cost-of-living differentials. Travel allowances and financial support for rural families should be standard components and separate from clinical funding packages. The province should monitor and publicly report service pricing trends and funding adequacy through an annual affordability review. These measures would ensure that purchasing power remains stable and that access to therapy does not depend on a family’s financial capacity.

System Governance and Transparency

Finally, systemic reform requires governance structures that prioritize accountability and collaboration. Autistic individuals and their families must have meaningful representation in decision-making bodies overseeing the OAP. The Ministry should adopt transparent data practices, including regular publication of waitlist figures, regional service levels, and program outcomes. Inter-ministerial coordination, spanning children’s services, education, health, and social assistance, is essential to address the interconnected nature of needs identified in this report. Building trust requires not only adequate funding but also open communication and shared responsibility.

RECOMMENDATIONS
POLICY, FUNDING, TRANSPARENCY

Summary of Direction

Collectively, these recommendations outline a roadmap toward a coherent, needs-based, and lifespan-oriented autism service system. Implementing them would shift Ontario from a reactive, fragmented approach toward one that values early intervention, sustained support, and dignity for autistic individuals and their families. Each reform proposed here is both practical and urgent, grounded in the lived evidence presented through the voices and data of the OAC community.

The evidence could not be clearer: Ontario's autism community is in crisis, and meaningful system reform can no longer be delayed. With over 64,800 children and youth still waiting for core funding and the number of active Core Clinical Services funding agreements declining slightly since June 2025, it is more important than ever for the Ministry of Children, Community and Social Services to pay attention. The Ontario Autism Coalition's recent Freedom of Information (FOI) request, reflected in our October 2025 OAP at a Glance data, confirms what families have been saying for years: progress has stalled, and public confidence in the OAP continues to erode.

The Ministry must immediately commit to transparent reporting, indexed and equitable funding, and a full review of high-cost, low-impact pillar programs. It must restore accountability and rebuild trust through collaboration with families, service providers, and advocacy organizations. Every child and youth registered with the Ontario Autism Program deserves timely, needs-based support. The data are now undeniable — the time for action is now.

APPENDIX

A. AUTISM PREVALENCE (0-18) CALCULATION

Based on the most recent data obtained through a Freedom of Information (FOI) request, as of August 6, 2025, there were 84,405 children and youth registered with the Ontario Autism Program (OAP). Because OAP registration requires a formal ASD diagnosis, this figure represents a reliable minimum estimate of the number of autistic children and youth in Ontario (0-18). Using the 2021 Statistics Canada Census, which reports approximately 2.7 million Ontarians aged 0–18, this equates to a prevalence rate of 3.17%, or roughly 1 in 32 children and youth. This estimate exceeds the earlier 1 in 50 prevalence reported in the 2019 Canadian Health Survey on Children and Youth (CHSCY) and likely remains an undercount, as it excludes those awaiting or unable to obtain a diagnosis. While new CHSCY data are pending, this calculation provides an interim estimate of autism prevalence in Ontario. This estimate will be updated in 2026 when new census data becomes available from Statistics Canada.

84405 : 2700000 = 1 : **32**

84405 : 2700000 = 1 : 31.988626266216
= 0.031261111111111 : 1
= 5627 : 180000

Formula:

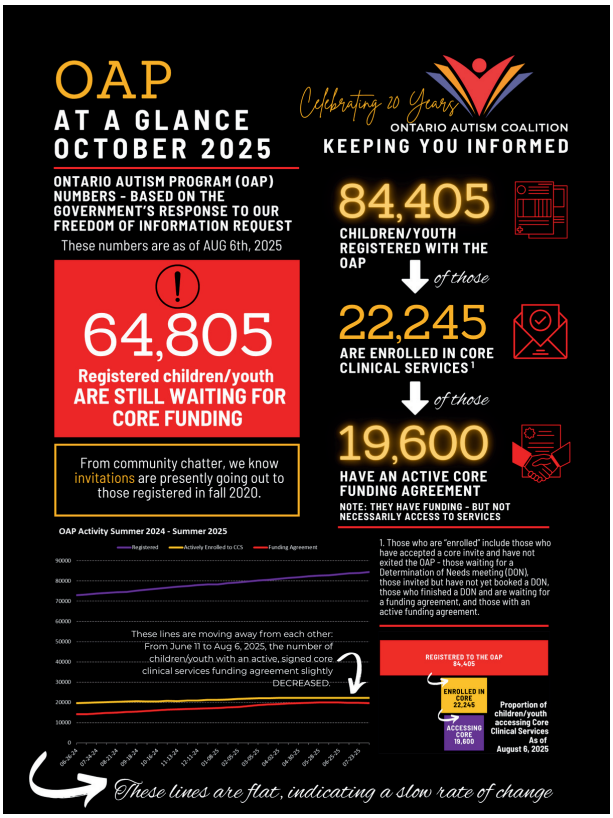
Prevalence Estimate = New and pre-existing cases / Population size * 100

Prevalence Estimate = 84,405 diagnosed / 2,700,000 (population estimate 0-18) * 100%

Prevalence Estimate = 3.13%

B. OAC - MCCSS FOI INFOGRAPHIC: June 2025

C. OAC - MCCSS FOI INFOGRAPHIC: October 2025



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