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Ending the Wait

Evolving developmental services to support more people with limited resources



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This resource offers a series of arguments and recommendations related to the waitlist for developmental services in Ontario. It is meant to inspire discussion, and to bring greater clarity and direction to *Journey to Belonging: Choice and Inclusion*, the province's strategy for developmental services. It revolves around several key ideas:

- It is possible to support more people within the existing developmental services budget.
- Systemic change and budget increases are both needed to achieve significant waitlist reductions.
- Investments in planning, system navigation, and crisis prevention will reduce the need for expensive downstream health and clinical services.
- Individualized housing has been proven to be more cost-effective and to support better outcomes compared to group housing.
- Families must be recognized and better supported in situations where they provide significant care and support.
- A 'money follows the person' approach will address longstanding inequities in the system.

1. Introduction

There are currently more than 50,000 adults waiting to access developmental services in Ontario.[1] This means that about one in every three Ontario adults with a developmental disability is officially waiting to access a needed service or support.[2]

There are eleven distinct adult developmental service waitlists. If we are serious about reducing those waitlists, each one requires a distinct strategy and approach. Community Living Ontario strongly believes that the waitlists will be most effectively addressed by strategies that increase choice and control among people supported, and that prioritize:

- Increasing independence among people who have a developmental disability;
- Recognition of people’s decision-making capacity, and of the support they need to make decisions;
- A continued evolution away from congregated housing and programs.

Building on these values, this document puts forward evidence-based ideas and guidance on how Ontario can increase people’s well-being and quality of life, evolve the developmental service system to support more people with limited resources, and reduce waitlists.

2. An Overview of Developmental Service Waitlists in Ontario

There are eleven waitlist categories across two streams in Ontario’s adult developmental service system. These are referred to as ‘service registries’ by the Ministry of Children, Community and Social Services (MCCSS), and consist of the following:

A. Supportive Living Service waitlists

1. Group home
2. Intensive support residence
3. Host family
4. Supported independent living

B. Community Support Service waitlists

5. Community participation
6. Caregiver respite
7. Employment supports
8. Professional and specialized supports
9. Adult Protective Service Worker (APSW)
10. Community Networks of Specialized Care (CNSC) [3]

Additionally, the Passport program has its own waitlist; while every adult eligible for developmental services funding gets immediate access to the \$5,500 annual Passport minimum, there are more than 30,000 people waiting to receive their full allocation.[4]

3. A Short History of Official Attention to Adult Developmental Service Waitlists

Over the past ten years, a series of blue-ribbon reports have taken a close and critical look at developmental service waitlists:

- In 2014, the Ontario Select Committee on Developmental Services stated that “all people have a right to appropriate and timely supports and services throughout their lives.” The committee recommended that “the provision of developmental services and support should be mandated and waitlists eliminated. The elimination of existing waitlists must be the top priority for government.”[5]

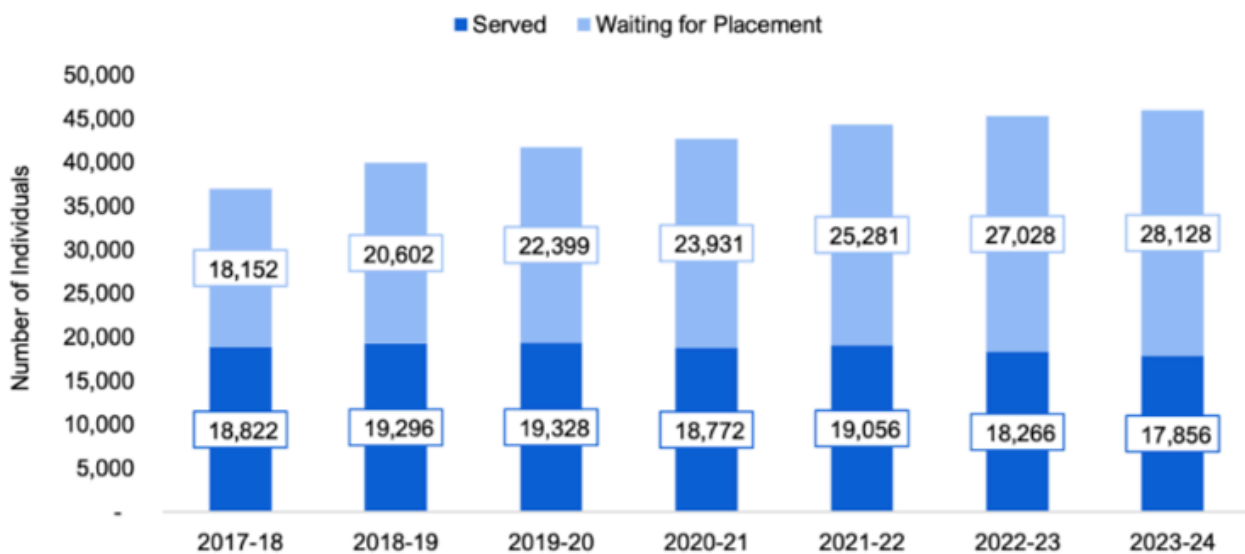
The Select Committee, which included former Minister of Health and Deputy Premier Christine Elliott, and current Minister of Health and Deputy Premier Sylvia Jones, described “serious barriers to support across the province including long waitlists for many services; repeated, onerous, and invasive assessments; the abrupt termination of children’s services at the age of 18 and school-based services at age 21; unmet health needs due to inadequate primary and dental health care; and a serious lack of services and supports in northern, remote, and First Nations communities.” All of these issues are still relevant today.

- Also in 2014, the Auditor General of Ontario reported that 17,900 people were accessing Supportive Living Services, and 12,800 were on the official waitlist. Its review noted that the number of people accessing these services grew by just 1% between 2010 and 2014, “while spending on those services and supports rose 14%, to \$1.16 billion. Although a portion of this funding increase was intended to accommodate 1,000 more people over four years, only 240 more were being served by the end of the third year.”[6]

- In 2016, the Ontario Ombudsman published *Nowhere to Turn*, a scathing examination of the negative effects that service shortages and waitlists have on people with developmental disabilities and their families. It provides heart-wrenching accounts of what people were facing at the time, and what many continue to face to this day.
- In 2020, the office of the Auditor General again turned its attention to developmental services, with similar findings. The Auditor General’s ‘value-for-money’ analysis offered further insight into an underappreciated aspect of the waitlisting system, noting that in March 2020, 34,159 people were waiting for Community Support Services; of these, the majority (20,480, or 60% of those waiting) were receiving no services at all.[7]
- In 2024, the Financial Accountability Office of Ontario (FAO) offered a striking view into the waitlist for Supportive Living Services, showing that the system is housing 5% fewer people than it did in 2018, while the waitlist has grown by 55% (as shown in the chart below, which is taken directly from the FAO report).

Figure 6.3

Eligible individuals served and on waitlists for Developmental Services Supportive Living, by fiscal year



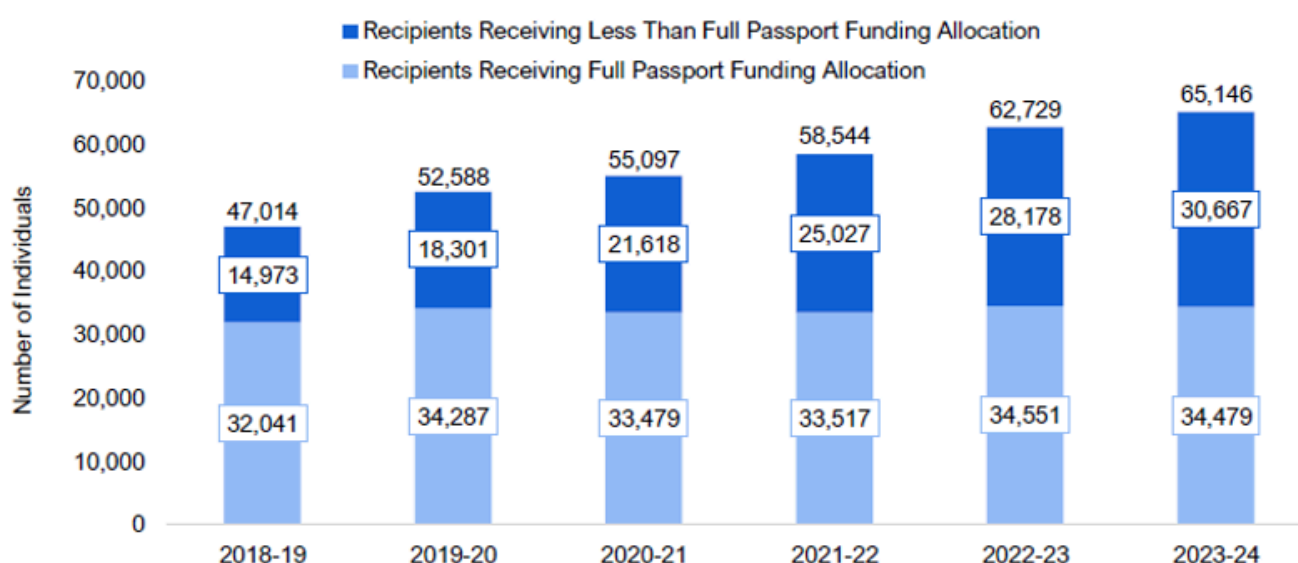
Note: 2023-24 values are interim as of December 2023. The number of people waiting for placement represents clients who have had their needs assessment and does not include those who are seeking placement but are still unassessed. In addition, the values for waiting for placement may include individuals already in a placement who are waiting for a different placement.
Source: FAO analysis of information provided by MCCSS

The FAO noted that, in 2018, there were more people receiving Supportive Living Services than waiting for them. Six years later, the number of people accessing those services has actually dropped, and the number waiting is now 60% higher than the number served.

The FAO also provided a helpful overview of those waiting for their full Passport allocation. The number of people receiving any amount of Passport funding grew from 47,000 to 65,000 over five years, an increase of almost 40%. As of March 2024, about 35,000 were receiving their full allocation, and 31,000 were receiving less than their full allocation.

The number of people receiving their full Passport allocation has remained relatively steady, hovering between 32,000 and 35,000 people each year. In contrast, the number waiting for their full allocation grew by 105% over five years (as shown in the chart below, again taken directly from the FAO report).

Figure 6.4
Number of people receiving Passport funding, by fiscal year



Note: 2023-24 values are interim as of December 2023.
 Source: FAO analysis of information provided by MCCSS.

4. The Ontario Waitlist Class Action

It must be noted that there is currently a certified class action against the Government of Ontario on behalf of people who were on a waitlist for supportive living services, caregiver respite services and supports, or Passport funding between July 2011 and December 2018.[8]

In its analysis of the class action claim, the Ontario Court of Appeal judged that the Government of Ontario likely does not have a constitutional obligation to eliminate developmental service waitlists. However, the court did not completely rule out that possibility, writing that this dimension of the claim may “warrant further consideration at trial.”

On the other hand, the court judged as more reasonable the lead litigant's claim that Ontario has been negligent in its operation of developmental service waitlists, even when accounting for budgetary restraints. The court notes that the class action:

"... alleges that the conduct of Ontario in assessing, approving, and then placing class members into an incoherent and irrational waitlist process visits harm to their security of the person. Read in this light, the complaint is not simply about state inaction or delay – i.e., the failure to alleviate the class members' vulnerabilities that already exist due to their developmental disabilities. The complaint is about harm to their security of the person, including their psychological integrity, that is alleged to occur from state action."

The original claim made the case that the Government of Ontario "arbitrarily prioritizes certain eligible individuals over others," rather than "proceeding on a linear 'first-come-first-served' model or 'needs-based' model."

The developmental services prioritization process is a points-based system that identifies people in crisis situations (i.e., by need and access to resources) and pushes those people up the waitlist. It is arguable that terms like 'incoherent,' 'irrational,' and 'arbitrary' are not necessarily accurate descriptors of the DSO assessment and waitlisting process, which is, at least in theory, trackable and comparative across applicants.

Of course, there will always be variability in the outcomes of human-led processes and no system is perfect. Triaging access to services will always be messy and problematic in a resource-constrained system. The process depends on people contacting Developmental Services Ontario when their situation changes; on the capacity and willingness of organizations to accept people into service; on the availability of housing in Ontario communities; on the availability of qualified professionals (e.g., doctors, nurses, psychologists, etc.) to offer third-party support, etc. – and this is only scratching the surface.

The Auditor General identified this issue in 2014, noting that:

"Eligible people who need residential services are assessed and prioritized for services. However, placements go to people who are the best fit for the spaces that become available, instead of those assessed as having the highest priority needs. In two of the regions we visited, for example, 18% and 33% of those placed during 2013/14 had a lower-than-average priority score on their regional wait lists." [9]

Even if the class action succeeds and the Government of Ontario is ordered to make changes, it will still face the fantastically complex and difficult problem of fixing the developmental service waitlists, which implies fixing the developmental service system.

As we have noted elsewhere, we believe that *Journey to Belonging*, while moving in the right direction, is not enough. The province needs a more detailed, expansive, and evidence-based strategy.

5. Understanding Developmental Services Spending and Waitlists

In the five fiscal years between 2013-14 and 2018-19 (the last being the year of transition from a Liberal to Progressive Conservative government), the waitlist for Supportive Living Services grew from 12,808^[10] to 20,602 unique individuals,^[11] an increase of 61% (12.2% per year on average).

In the four fiscal years from 2018-19 to 2022-23, the waitlist for Supportive Living Services grew from 20,602 to 27,028 unique individuals,^[12] an increase of 42% (8.4% per year on average). This is a slightly improved record, despite the fact that the number of people supported decreased over the same period.

Waitlists have continued to expand even with increased spending in the sector:

- From 2018 to 2024, the cost of living in Canada increased by 21%,^[13] spurred by steep inflation during the COVID-19 pandemic.
- During the same period, spending on developmental services grew from \$2.29 billion to \$3.33 billion, an increase of 46% over six years.^[14] In 2023-24, this amounted to:
 - \$2.26 billion for Supportive Living Services
 - \$555 million for Passport
 - \$513 million for agency-provided Community Support Services^[15]

(As a comparator, the Government of Ontario spent \$59.3 billion on health care in 2017-18,^[16] and \$79.9 billion in 2023-24,^[17] an increase of 35%.)

The FAO made the case that increased spending on Supportive Living Services could be attributed to “inflation and rising placement costs for new intakes.”^[18] We would highlight additional factors that, while overlapping to some extent with inflation, bring greater detail to the cost pressures faced by the sector. These include:

- Above-inflation wage and benefit increases due to collective bargaining in a widely-unionized sector.

- Increasing use of third-party human resource providers to address widespread staff shortages.
- Increasing use of for-profit care providers (known as ‘Outside Paid Resources’) when traditional non-profit agencies reach capacity limits.
- The \$3 ‘pandemic pay’ wage increase that was made permanent in 2022.
- Many developmental service agencies have implemented changes (e.g., building modifications, staff training, additional services including nursing and hospice support) that allow them to support people to age in place, which supports increased quality of life and reduces pressure on the province’s health and long-term care systems. (While this may increase costs within developmental services, it often means a net savings for the province overall).
- The system has continued to invest in capital assets (i.e., residences) over several decades. As capital assets age, maintenance and repair costs increase.

[**The Accountability Problem**]

The Government of Ontario has a pervasive transparency deficit. For example, none of the waitlist data provided in this document is publicly available from the Ministry of Children, Community and Social Services. The public must rely on the Auditor General, Ombudsman, and Financial Accountability Officer to obtain access to detailed data on the sector.

This is a critical barrier to policy and program development and innovation, particularly in a period of rapid turnover at the minister, deputy minister, assistant deputy minister, and director levels within MCCSS. The most important system experts, including self-advocates, family members, agency leaders, and researchers are unable to access crucial information and data.

6. Reducing the Waitlists

We would make the case that addressing the eleven adult DS waitlists will require a series of overlapping but distinct strategies. Aside from the Passport waitlist, none of these strategies will be straightforward or easy. We strongly believe that the problem will be most effectively addressed by strategies that are centred on:

- Increasing independence among people supported.

- Evolution away from congregated housing and programs.
- The recognition of people’s legal capacity, and the growth of supported decision-making to increase choice and control.
- Respect for the wishes of people with developmental disabilities.

These themes, long at the core of the community living movement, are reflected throughout *Journey to Belonging*. As that strategy notes:

“... we are in reach of community inclusion and true belonging. Self-advocates, families and service providers have been at the forefront of this important social change through the community living movement. They have worked long and hard to change perceptions about what it means for people with developmental disabilities to live a good life and the kinds of supports that will help them achieve that. People and their families expect to enjoy all the rights and opportunities that other members of society take for granted, like going to school, having a job, receiving healthcare services, and having real choices and control over the decisions that affect them. Significant progress has been made over the years, but we still have work to do.”

These themes inform each of the arguments and recommendation that follow.

a. Group Home and Supported Independent Living Waitlists

1. Create clear pathways to cost-efficient individualized housing

Community Living Ontario has for decades called for a move away from group settings and toward supporting people in non-specialized housing. Our 2021 report, [Building a Full Life + a Home of One’s Own in the Community](#), makes a detailed case for this move, and we have elsewhere brought attention to [successful individualized housing models](#), the advantages of [separating housing](#) from other disability-related supports, the costly problem of [over-support in group homes](#), and our province’s [over-reliance on long-term care facilities](#) for shelter.

The Ministry’s own research has shown that:

- The cost of supporting people can often be reduced when they move from group living to non-specialized settings in the community.
- A strategic move away from group housing has allowed some Ontario agencies to sell capital assets (thereby reducing repair and maintenance costs related to those assets),

and use the resulting funds to support more people in individualized settings.

- People who move into individualized settings often experience improved health and well-being, a finding that has been reported in multiple studies from around the globe.

Perhaps most importantly in the context of the current discussion, MCCSS research found that “agencies were able to increase system capacity with this service delivery shift and as a result some individuals who had been waiting for residential services are now accessing residential supports.”[19]

This reality goes well beyond Ontario. For example, a series of benchmark studies in the United States found that community-based housing models are substantially less costly to governments compared to congregate settings on the whole, even though community-based settings might be more expensive for a small number of people with very complex needs.[20]

Given the overwhelming evidence, we believe that the best way to reduce the waitlist for group residential housing is to build capacity in Supported Independent Living (SIL), and to drastically shift provincial policy away from group living. This can be accomplished through several streams, including:

- Stop the practice of requiring youth transitioning from the child welfare system to accept group home vacancies in order to access all the funding and support for which they are eligible. Allow funding to follow people into homes of their choice in the community. In many cases youth will access their own networks for housing, foregoing the need to use a group home or SIL spot.
- Spread the practice wherein agencies check in with each person they support at least once per year, to understand if they want to move to a different setting, with an emphasis on building people’s capacity to move from group living to SIL.
- Make it easier for agencies to leave group home vacancies unfilled, and to implement a process to gradually empty, close, and sell or repurpose residential properties. The proceeds would then be invested in expanding the number of people supported in SIL.
- Building on the Canada-Ontario Housing Benefit, expand rent subsidies to address the unfairness in housing-related funding between those living in group homes versus SIL. Whereas those in group homes have their ODSP shelter portion effectively subsidized by agency funding, many people who choose to access housing in the community must rely on ODSP alone. The inadequacy of ODSP limits choice of residence, pushes people into substandard housing, and acts as a disincentive to leave congregate housing.

Many Ontario organizations have shown that it is possible to increase the supply of SIL spaces. They have built relationships with landlords and developers, worked with municipalities to make rent subsidies available to people labelled with developmental disability, and collaborated with other non-profits to create stable and predictable housing arrangements. We are convinced that there are substantial gains to be made if these strategies spread more widely throughout the province.

2. Fund people to stay in their family home

At the present time, official policy dictates that people must move into an agency-controlled setting in order to access MCCSS funding for developmental services supportive living. To a great extent, funding is available mainly to youth leaving the child welfare system and to people in situations of severe crisis.

There is a deep irony in the fact that people can access funding if they move in with a 'host family,' but not if they wish to stay with their own family. There is overlap on this issue with families who relinquish their children to child welfare agencies so that the children can access services and supports that are otherwise being denied to them.

Unofficially, there are (conservatively) hundreds of adults who continue to live with family members and who have gained access to significant developmental services funding. These tend to be people who have found that moving into an agency-managed setting does not meet their needs, and who have returned to live with family members (sometimes after multiple attempts to be moved out).

Among the 28,000 people[21] on the Supportive Living Services waitlist is a group who are approaching the top of the list, but who are not in the highest state of crisis. Often, it is the presence of one or more family caregivers that keeps their needs score from reaching crisis level. Unfortunately, this type of situation can take a severe toll on the health and well-being of the person and their supporters. When they do finally reach enough of a crisis to access funding, they often face a 'take it or leave it' offer to move into a housing situation that upends every part of their life, with all the negative outcomes (including anxiety and challenging behaviours) that this may entail for the person, their family, and agency staff.

While not everyone wants to live with their family as an adult, many people do. In our triaged system (and given the severe shortage of affordable housing in the province), it just makes sense to offer funding to those in this kind of situation – both for people's well-being and to take pressure off of the Supportive Living Services waitlist. Furthermore, if we are serious about choice, control and inclusion as espoused in *Journey to Belonging*, we cannot make funding contingent on where a person lives.

For decades, family groups have been calling on the province to offer funding that people and families can use to manage their own supports. They have also called on the province to allow people to access developmental service funding even if they wish to remain at home with family. There are many models available, including those outlined by [Community Living Ontario](#), the [Individualized Funding Coalition for Ontario](#), and the [Provincial Executive Directors' Group](#). This step would be a cost-effective way of removing potentially thousands of people from the Supportive Living Services waitlist. It would also increase the choice, control, health, and well-being of people and families.

3. Invest in Adult Protective Service Workers

The waitlist for Adult Protective Service Workers (APSWs) has skyrocketed, nearly doubling from 3,300 to 6,300 between 2019 and 2023.[22] Unfortunately we do not have data on the factors related to this increase. However, it seems likely that this is connected to the rapid growth of young people entering developmental services from the child welfare system, many of whom have been diagnosed with Fetal Alcohol Syndrome, struggle with mental health issues, and strongly prefer to live outside group settings.

MCCSS has consistently worked to support the human resource needs of developmental service organizations, with a focus on supply, recruitment, and training of Developmental Service Workers (DSWs). The Developmental Services Workforce Initiative (DSWI) is perhaps the most visible current example of this work.[23]

If the developmental service system is to be successful in achieving greater individualization, moving away from resource-intensive group living, and meeting people's specific housing needs and preferences, it will be important for MCCSS to prioritize the development, training, and adequate compensation of a strong APSW workforce. This will allow for greater independence and well-being among people supported, and will reduce the involvement of the health, emergency service, and justice sectors in the lives of (especially young) people with developmental disabilities.

Investment in the APSW workforce could also be considered an important plank of the province's action plan to end gender-based violence[24] and its anti-human trafficking strategy.[25] APSWs bring valuable community development and harm reduction skills to the sector, helping to fill a gap between DS agencies (where staff are often unprepared to support people engaging in risky behaviour, substance use, etc.) and broader social service agencies (where staff often know little about developmental disability).[26]

b. Waitlists for Specialized Supports / Community Networks of Specialized Care

These two waitlist categories revolve around (1) support with communicating, e.g., language skills training, speech therapy, etc., (2) mental health, and (3) psychological and other specialized services generally related to challenging behaviour.[27] Services provided through Community Networks of Specialized Care (CNSC) are directed specifically for people with “extraordinary medical and/or behavioural support needs.”[28]

As of 2023, there were nearly 12,000 people waiting for professional and specialized supports, and about 360 people waiting for access to a CNSC.[29]

1. An ounce of prevention is worth a pound of cure

If we take a 30,000-foot view of the well-being of people who have a developmental disability in Ontario, there is a lot to be concerned about. People living with this label:

- Are more likely to be hospitalized repeatedly.
- Are more likely to become stranded in the hospital because there is no more appropriate place for them to go.
- Are more likely to be living in a long-term care facility, even at a young age.[30]
- Are much more likely to be victims of violent assault, and to experience physical, emotional, and sexual abuse.[31]

Nearly one-third of adults with a developmental disability in Ontario were prescribed at least one antipsychotic medication between 2009 and 2016, despite the fact that the majority had no relevant diagnosis of a major mental illness. And when a person is prescribed one medication, it is very likely that they will be prescribed more, including anti-depressants and benzodiazepines.[32]

Many would contend that the overwhelming purpose of this overmedication is to control the behaviour of people who have experienced significant trauma, and who are living in situations that make them anxious, frustrated, and depressed. Unfortunately, the approach is largely ineffective:

- Several studies show no difference between antipsychotics and placebo in managing challenging behaviours.[33]

- A number of guidelines in multiple jurisdictions advise against the use of antipsychotics for challenging behaviour, including the *Frith Prescribing Guidelines for People with Intellectual Disability*, guidance from the United Kingdom National Institute for Health and Care Excellence, the World Psychiatric Association, and the Canadian consensus guidelines for family physicians, which clearly states, “Do not use antipsychotic medications as a first-line or routine treatment of ‘behaviours that challenge’.”

Community Living Ontario has been privy to countless situations where a person has lost their main caregiver to death or ill health. So often in these cases, the person is forced to run the gauntlet through confusing legal processes, uninformed health systems, biased capacity assessments, disordered regional planning, and under-resourced service agencies. They very quickly go from the predictability and comfort of living in a cherished home and community, to the shock and uncertainty of a life in services. Too often, they are given little or no choice in where and with whom they live, and where and with whom they spend their days. When they react – as anyone would – with a decline in mental health, too often medication is the answer.

On the opposite side of the coin, Community Living Ontario has also been privy to situations where a person in a similar situation (i.e., the loss of a main caregiver) has had access to planners, system navigators, and/or advocates who were able to slow down and redirect the transition process. This can include adequate time to grieve, protection from the worst parts of the system, efforts to understand their needs and goals, and assistance with finding a living situation that supports well-being and quality of life. In other words, actions that work to prevent situations where anyone with a prescription pad or behaviour plan would need to enter the picture.

While clinical supports will continue to have value, Ontario urgently needs to invest in crisis prevention and planning services that help people make sense of a disordered system, reduce trauma when transitioning into care, and forego the need for costly health and psychiatric services.

c. The Host Family Waitlist

The Host Family program (sometimes called ‘Family Home’) has seen the most striking long-term waitlist growth across categories: from 833 people in 2014, expanding by more than 200% to 2,559 in 2023.[34] While we don’t know how many people on this waitlist have also applied for a group home or supported independent living (SIL) placement, it is likely that there is significant overlap.

The Host Family program is almost certainly experiencing the same issues Ontario is seeing in the child welfare sector. According to the Ontario Association of Children’s Aid Societies

(OACAS), the availability of foster homes in the province has dropped by a third since 2020. [35] The challenges underlying this issue will be familiar those in the DS sector:

- The cost-of-living and housing crises have reduced the financial flexibility and space that is necessary for foster placements in Ontario households;
- It is particularly difficult to find foster placements for children with complex needs;
- Many communities lack the services that potential foster families would need to provide a safe and secure environment for young people.

Recently, MCCSS proposed several changes to increase Host Family capacity. These changes generally revolved around increasing the number of placements within each host family, and loosening restrictions around combination foster/host family placements. These changes, which would have effectively supported the creation of semi-informal group homes, were problematic in several ways and do not appear to have been implemented.

Without access to data on current compensation levels for host families, it is difficult to comment on how finances might be playing a role in supply. It is our understanding that compensation varies across regions, agencies, and households, and (as with many elements of developmental services) there is a lack of transparency on this issue. We believe that low compensation rates, a lack of access to additional supports and services, a lack of public information about the program, and fears about their ability to provide adequate support are all acting as barriers to new host families.

Several agencies have expanded on the host family philosophy with programs like ‘friendly neighbours’ and ‘supportive roommates.’ In these programs, current or prospective members of a person’s informal social network receive compensation (e.g., a monthly stipend, a reduction in rent, etc.) to be available as needed to offer a range of support such as help with cooking and cleaning, grocery shopping, managing novel situations, and liaising with service providers. Forward-thinking organizations have leaned into these and other models (including APSW services) that provide ‘just enough’ support and increase the likelihood of success in more independent settings, which again offer cost advantages over other living options.

d. The Caregiver Respite Waitlist

The Ontario Caregiver Coalition (OCC) has brought attention to the significant financial hardship faced by people who provide support to a loved one with a disability. For example:

- 45% of Ontario’s caregivers are experiencing hardship because of their caregiving responsibilities.
- 20% have taken out a loan or line of credit to pay for support-related expenses.[36]

As the OCC also notes, caregivers often access savings to pay for respite and other staff, and/or reduce their employment in order to offer care themselves – both of which steadily erode their financial health. The financial assistance offered by the federal government (i.e., the Caregiver Credit) and the province (i.e., the caregiver amount) is limited and non-refundable, and therefore not helpful for people with low incomes.

The OCC has recommended three major actions that would increase support for people and their supporters, and that would reduce or delay the need for more formal types of support and care:

1. Provide direct financial support to unpaid caregivers in the form of a caregiver allowance;
2. Invest in and increase access to home and community care support services;
3. Improve access to direct funding programs, including Family Managed Home Care.

Community Living Ontario is supportive of all of these recommendations (and we expand on the idea of direct funding above). Ontario’s triaged developmental service system stands on the shoulders of family members who, from the time their loved ones with disabilities are born, must navigate systems that often do not understand or meet their needs. Additionally, families regularly see other households in very similar situations who are able to access higher levels and different types of support resulting in a concerning lack of fairness across the system.

Additionally, it must be noted that many people who opt for a Supported Independent Living placement depend on significant family involvement in their lives, even after they have moved out of a family home. Whereas current practice is to remove the respite portion of Passport funding after a person moves to SIL, we would argue that this funding continues to be crucial for the success of many SIL placements and should be maintained.

e. The Passport Waitlist

The Passport waitlist is in some ways the simplest, as it is a purely financial issue. If the average full Passport allocation is \$11,200 per year,[37] and 30,667 people are currently

receiving the minimum of \$5,500, it will take an additional \$175 million per year to clear the waitlist.

There is a strong case to be made that increased Passport uptake will decrease pressure on agency-based services, given that about three-quarters of Passport funding is used to pay for support workers and staffed day programs (including caregiver respite).[38] The more that people and families can pay for staff themselves, the more they will be able to avoid crisis situations that tip them toward agency care.

It is important to note that providing access to a full Passport allocation will not address the consistent underutilisation of the program. Each year, about \$700 million is budgeted for Passport, but recipients use less than \$600 million.[39] The fact that people must spend out-of-pocket and be reimbursed for Passport purchases is a key cause of this underspend; continuing the pandemic-era practice of making funds available up front as policy (rather than as a special request) would address this issue.

f. The Waitlist for Community Participation and Employment Supports

Currently, more than 30,000 people are waiting for community participation supports, i.e., funding to support them to engage safely in activities during the day. For many family caregivers, this means a ‘day program’ facility where people labelled with intellectual disability can go between 9:00 and 4:00. For others, it means funding to pay staff to assist them when they volunteer, play sports, visit the library, hang out with friends, etc.

There are also 12,000 people on the waitlist for employment supports, with many or most likely overlapping on the community participation support waitlist.[40]

Taken together, these two waitlists reflect the substantial diversity among people labelled with intellectual disability. There are those who need very little assistance in their day-to-day lives, those who need constant help during their waking hours, and people at every point along this spectrum.

Community Living Ontario has written elsewhere of jurisdictions that have moved away from congregate day programs and toward supporting people to engage more deeply with their local community – for example, being supported to join their local gym, volunteer at the community arena, or contribute to the maintenance of a community garden. This approach works to build people’s informal support networks and thereby reduces the need for paid staff.

Similarly, many developmental service organizations have long been at the forefront of paid mainstream employment for people labelled with intellectual disability. Thanks to our

engagement in the national Ready, Willing and Able employment initiative (which has supported more than 5,000 people to be hired across the country since 2014), Community Living Ontario knows that real employment with real wages (and without charitable elements like wage subsidies) is possible and scalable. And again, the more people are employed, the lower the demand will be for community participation funding.

Unfortunately, Ontario's ongoing transformation of employment services is demonstrably failing people who have an intellectual disability. Organizations offering these services have seen employment-related revenues drop below sustainable levels, while administrative requirements have skyrocketed. Many organizations are increasingly relying on MCCSS employment program funding to keep this work afloat and are facing incredible uncertainty, as we have shown in our recent report, [Tangled in Red Tape](#).

Though employment programs have been largely moved over and concentrated within the Ministry of Labour, Immigration, Training and Skills Development (MLITSD), MCCSS has a vested interest in the success of these programs in supporting people with intellectual disabilities to become more educated, more experienced, and more independent via skills building, networking, and employment. This is a huge and ongoing missed opportunity with direct costs for the province.

For more information:

Shawn Pegg

Director, Social Policy & Strategic Initiatives

Community Living Ontario

shawn@communitylivingontario.ca


Community Living Ontario is a non-profit provincial association that has been advocating for people who have an intellectual disability and their families for 70+ years. We proudly work alongside 122 local agencies and advocate on behalf of more than 100,000 people across Ontario.

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 www.communitylivingontario.ca

 info@communitylivingontario.ca

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Endnotes

[1] The Government of Ontario does not make developmental services ‘service registry’ (i.e., waitlist) data available to the public. As a member of several advisory groups in Ontario’s developmental service system, Community Living Ontario sometimes has access to unpublished waitlist information. Several recent verbal reports, using information from the province’s Developmental Services Consolidated Information System (DSCIS), have indicated that there are approximately 50,000 unique individuals on a waitlist for developmental services in Ontario.

[2] Statistics Canada estimates that 1.5% of Canadians have a developmental disability. See <https://www150.statcan.gc.ca/n1/pub/11-627-m/11-627-m2023063-eng.htm> for more information.

[3] For details of these programs, see <https://www.ontario.ca/document/2024-2025-mccss-service-objectives-community-services>.

[4] Financial Accountability Office of Ontario (2024). *MCCSS: Spending plan review*. <https://www.fao-on.org/en/Blog/Publications/FA2305-MCCSS>.

Many of these 30,000 would also be among the 50,000 people waiting for other types of support.

[5] Select Committee on Developmental Services (2014). *Inclusion and Opportunity: A New Path for Developmental Services in Ontario*. <https://www.ola.org/en/legislative-business/committees/developmental-services/parliament-41/reports/final-report>.

[6] Office of the Auditor General of Ontario (2014). *Residential services for people with developmental disabilities*. <https://www.auditor.on.ca/en/content/annualreports/arreports/en14/310en14.pdf>.

The original document reported a total of 14,300 people, which was later revised to 12,808 (as reported in the Ombudsman’s *Nowhere to Turn* report), and which we believe would have been the number of unique individuals.

[7] Office of the Auditor General of Ontario (2020). *Supportive services for adults with developmental disabilities*. https://www.auditor.on.ca/en/content/annualreports/arreports/en20/20VFM_07supportive.pdf.

[8] Koskie Minsky (2018). Class action against Government of Ontario over developmental services waitlists certified by Ontario Court. <https://www.newswire.ca/news-releases/class-action-against-ontario-government-of-ontario-over-developmental-services-waitlists-certified-by-ontario-court-702926551.html>.

While this class action draws on many of the same reports we have noted above, Community Living Ontario is not connected to lead representative plaintiff Briana Leroux, her litigation guardian Marc Leroux, or the legal firm supporting the action.

[9] Office of the Auditor General of Ontario (2014). Residential services for people with developmental disabilities. <https://www.auditor.on.ca/en/content/annualreports/arreports/en14/310en14.pdf>.

[10] Ombudsman of Ontario (2016). Nowhere to turn. <https://www.ombudsman.on.ca/resources/reports,-cases-and-submissions/reports-on-investigations/2016/nowhere-to-turn>.

[11] Financial Accountability Office of Ontario (2024).

[12] Financial Accountability Office of Ontario (2024).

[13] Bank of Canada Inflation Calculator. <https://www.bankofcanada.ca/rates/related/inflation-calculator>.

[14] Government of Ontario Public Accounts.

[15] Financial Accountability Office of Ontario (2024).

[16] Financial Accountability Office of Ontario (2019). *Ontario Health Sector: 2019 updated assessment of Ontario health spending*. <https://www.fao-on.org/en/Blog/Publications/health-update-2019>.

[17] Financial Accountability Office of Ontario (2024). Examining Ontario's 2024-25 Expenditure Estimates. <https://www.fao-on.org/en/ExpenditureEstimates?path=Health>.

[18] Financial Accountability Office of Ontario (2024).

[19] Ministry of Children, Community and Social Services (2021). Developmental Services Community-Based Residential Services 2019 Case Study. Available at https://communitylivingontario.ca/wp-content/uploads/2022/10/MCCSS_DS-Residential-Case-Study_2021.pdf.

[20] K.C. Lakin et al. (2008). Factors associated with expenditures for Medicaid Home and Community Based Services (HCBS) and Intermediate Care Facilities for Persons with [MR] services for people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 46(3), 200-214.

See also:

National Council on Disability (2012). Deinstitutionalization: Unfinished business. [https://laddc.org/files/NCD_UnfinishedBusiness_Paper_FINAL508\(102312\).pdf](https://laddc.org/files/NCD_UnfinishedBusiness_Paper_FINAL508(102312).pdf).

[21] Financial Accountability Office of Ontario (2024).

[22] Community Living Ontario staff notes taken during a 2023 presentation to the Provincial Network on Developmental Services.

[23] Developmental Services Workforce Initiative (2024). <https://dscorecomp.com/>.

[24] For more information, see <https://www.ontario.ca/page/ontario-stands-standing-together-against-gender-based-violence-now-through-decisive-actions-prevention-empowerment-supports>.

[25] For more information, see <https://www.ontario.ca/page/ontarios-anti-human-trafficking-strategy-2020-2025>.

[26] N. Reid et. al (2020). Building *Bridges to Housing* for homeless adults with intellectual and developmental disabilities: outcomes of a cross-sector intervention. *JARID*, 34(1). <https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12779>

[27] Government of Ontario (2024). 2024-2025 services delivered: DS professional and specialized services. <https://www.ontario.ca/document/2024-2025-mccss-service-objectives-community-services/2024-2025-services-delivered-ds-4>.

[28] Government of Ontario (2024). 2024-2025 services delivered: DS Community Networks of Specialized Care (CNSC). <https://www.ontario.ca/document/2024-2025-mccss-service-objectives-community-services/2024-2025-services-delivered-ds-1>.

[29] Community Living Ontario staff notes taken during a 2023 presentation to the Provincial Network on Developmental Services.

[30] Health Care Access Research and Developmental Disabilities (2019). *Addressing gaps in the health care services used by adults with developmental disabilities in Ontario*. Toronto: HCARDD.

[31] Statistics Canada (2018). *Violent victimization of women with disabilities, 2014*. <https://www150.statcan.gc.ca/n1/pub/85-002-x/2018001/article/54910-eng.htm>.

[32] T. Gomes et al. (2019). *Antipsychotic initiation among adults with intellectual and developmental disabilities in Ontario: a population-based cohort study*. <https://pmc.ncbi.nlm.nih.gov/articles/PMC6677990>.

[33] P. Tyrer et. al (2008). Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomised controlled trial. *The Lancet*, <https://www.sciencedirect.com/science/article/abs/pii/S0140673608600720>.

S.I. Deutsch & J.A. Burket (2021). Psychotropic medication use for adults and older adults with intellectual disability; selective review, recommendations and future directions. *Progress in Neuro-Psychopharmacology and Biological Psychiatry*. <https://www.sciencedirect.com/science/article/pii/S027858462030333X>.

L. Ramerman (2019). Off-label use of antipsychotic medication in people with intellectual disabilities: adherence to guidelines, long-term effectiveness, and effects on quality of life. <https://research.rug.nl/en/publications/off-label-use-of-antipsychotic-medication-in-people-with-intellect>.

[34] Community Living Ontario staff notes taken during a 2023 presentation to the Provincial Network on Developmental Services.

[35] Ontario Association of Children's Aid Societies (2024). OACAS Responds to Ontario Ombudsman's Investigation into the Use of Hotels, Motels, Offices, and Trailers as Placements for Children and Youth. <https://www.oacas.org/2024/09/oacas-responds-to-ontario-ombudsmans-investigation/>.

[36] Ontario Caregiver Coalition (2024). Pre-budget submission 2024. https://www.ontariocaregivercoalition.ca/files/ugd/675ebd_ea3764b907494cd58cdd77d360ea78d0.pdf.

[37] According to the Financial Accountability Office of Ontario, 30,667 people received the Passport minimum in 2023-24 (i.e., \$168,668,500 in total). With a total Passport spend of

\$555 million that year, this means that the 34,479 people receiving a full Passport allocation accessed \$386,331,500, or \$11,205 per person on average.

[38] Community Living Ontario staff notes taken during a 2023 presentation to the Provincial Network on Developmental Services.

[39] Information provided by MCCSS to Community Living Ontario.

[40] Community Living Ontario staff notes taken during a 2023 presentation to the Provincial Network on Developmental Services.