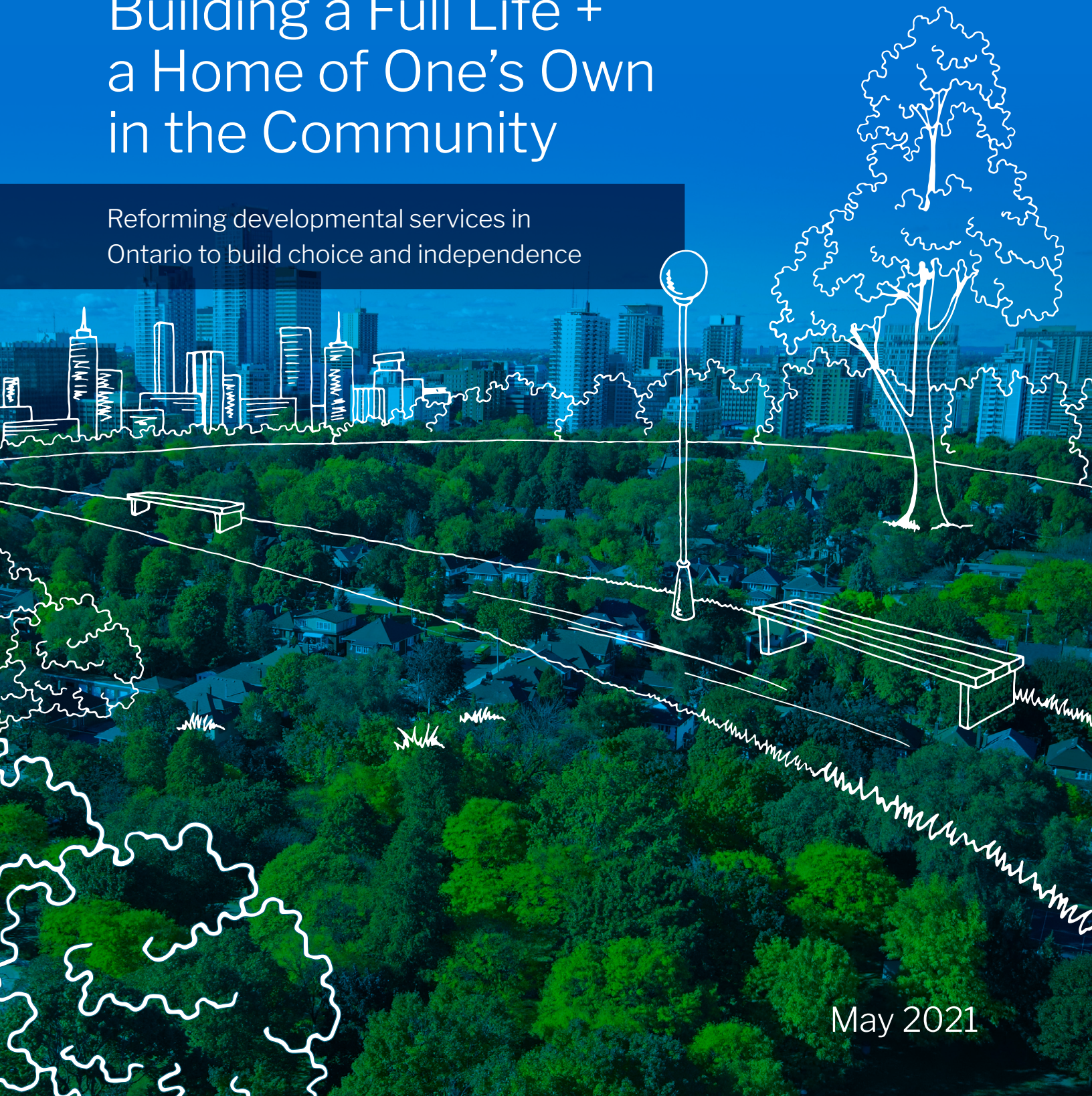


# Building a Full Life + a Home of One's Own in the Community

Reforming developmental services in  
Ontario to build choice and independence



May 2021





## Foreword

In 2016, Community Living Ontario released *Building a Full Life and a Home of One's Own in the Community through Direct Funding*, which presented a plan for the expansion of direct funding for people who have an intellectual disability.

Building a Full Life envisioned a developmental services system that supports individuals and families to have greater power, control and choice in the services and supports they need. Building on decades of work in disability rights and anti-institutionalism, it sketched out a road map toward typical lives and full inclusion.

This document builds on the original Building a Full Life and expands its focus. It outlines three main reforms that will lead the provincial government, service agencies, families, and people themselves on a path to greater personal choice and belonging in their communities:

- The expansion of direct funding
- An evolution away from congregated adult day programs
- A growth in opportunities for people to live on their own with appropriate supports

As a province, our goal must be to support people to create typical lives in their communities. We must stop seeing and categorizing people through the label of intellectual disability, and start seeing people as individuals with unique strengths and goals for their lives.

This is the end goal and guiding vision of the People First and community living movements, and – thanks to decades of previous work on which this report builds – it is well within reach.

While we cannot claim to have all the answers, we hope that this document provides a spark to take our sector to the next level in its evolution.

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## Executive Summary

Ontario is lagging behind other jurisdictions in policy and programs that support people who have an intellectual disability to gain autonomy, control and choice in their lives. There are clear steps the province can take that will improve the quality of life of people labelled as having an intellectual disability, while decreasing the per-person cost to government and reducing the waitlist for developmental services and supports.

This discussion paper puts forward recommendations to increase direct funding and supported independent living, and to decrease congregation in adult day services. It builds on lessons learned in other jurisdictions that, more and more, treat people who have an intellectual disability as unique individuals rather than members of a labelled and stigmatized population.

**The central purpose of this paper is to show that change is possible.** It draws on information from across Canada, the United States, the United Kingdom and Australia to paint a picture of ongoing evolution away from the negative practices of the past, and a vision wherein:

- People who have an intellectual disability are assumed to have the capacity to – with supports tailored to their needs – have a leading role in decisions that affect their lives, and reside in the community with a great deal of autonomy and belonging;
- People who have an intellectual disability have access to the same range of housing options as the general population;
- People who have an intellectual disability are increasingly supported to live without reference to this label;
- Ontario is seen as a leader in individualized and rights-based support to people labelled as having an intellectual disability.

## Summary of recommendations

This discussion paper makes specific recommendations to the provincial government related to direct funding, adult day supports and supported independent living. The recommendations are meant to provide high-level guidance and direction, leaving room for regional and organization-specific development and innovation. They include the following:

### Expanding direct funding:

- Offer a direct funding option to all adults who are eligible for developmental service funding through the Ministry of Children, Community and Social Services, regardless of the level of assessed need for services and supports.
  - Make direct funding available via “Expanded Passport,” a new program that fits within the existing Passport infrastructure, with the following key changes:
    - Funded services and supports will be expanded to include all items available via block-funded agency agreements and the existing Passport program. The cost of services and supports set out in annual plans must be equal to or lower than those provided via block-funded agency agreements.
    - Plan managers (i.e., people themselves, family members or close personal friends, or transfer payment agencies) will be approved using clear and transparent guidelines, and will develop and submit annual individualized plans with clear goals and outcomes. Plans must address:
      - i. A detailed outline of services and supports that will be purchased from agencies and/or individuals (including planning supports),
      - ii. Additional out-of-pocket funds to be contributed by people and family members (note that these should not lead to reductions in program funds), and
      - iii. The role of in-kind and unpaid supports from personal support networks (often referred to as ‘natural supports’).
- It is highly recommended that more intensive plans (e.g., requiring more than \$50,000 in program funds) require the engagement of facilitation and management support.
- Advance funding will be made available on a quarterly basis, with a requirement for regular financial reporting to the funding/oversight agency.

- Abuse prevention and reporting will be a key focus, particularly in the planning and approval stages, with (at minimum) annual meetings required between plan managers, the people accessing supports, and funding/oversight agency representatives.
- To support fairness across employment situations, minimum rates for the payment of Personal Support Workers and other staff will need to be established. Funding levels must account for inflation, coverage of group health benefits, liability insurance and membership in relevant professional bodies.
- Initiate research to understand the real per-person costs of developmental services in a representative sample of transfer payment agencies and Outside Paid Resource organizations, in preparation for the coming-into-force of the new “funding entities” described in section 18 of the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*.
- Implement pilot projects that develop personal budgets for at least 100 people currently supported by a transfer payment agency and/or Outside Paid Resource. Ensure the involvement of the individuals supported, family members and other supporters, and independent facilitators where available.

### De-congregating adult day supports:

- Repeal paragraph 6 of subsection 3(5) of the Ontario Employment Standards Act (i.e., “This Act does not apply with respect to... An individual who performs work in a simulated job or working environment if the primary purpose in placing the individual in the job or environment is his or her rehabilitation.”). This will eliminate the practice of paying employees who have an intellectual disability a pittance, and end once and for all the fiction that people are being rehabilitated or trained in sheltered workshops for years at a time.
- Make innovation funding available to developmental service agencies who wish to evolve away from congregated adult day supports.
- Highlight the evolution toward individualized supports for an active life in community as a key element of the province’s forthcoming developmental services reform agenda.
- Set clear and ambitious targets for the market-based employment of people who have an intellectual disability among Service System Managers, including those currently operating (i.e., in the Hamilton-Niagara, Muskoka-Kawarths and Peel regions) and those slated for future implementation.



### Supported independent living:

- Prioritize investment in geographically distributed, semi-independent, affordable housing options (including rental and home ownership). Implement enabling factors including rent supplements, portable housing allowances, and municipal development requirements mandating a proportion of affordable units for people who have intellectual disabilities within new builds.
- Separate developmental housing and support funding envelopes to increase flexibility in the system, and to increase people's control over their living situation.
- Create a dedicated ten percent allocation of National Housing Strategy funding for the developmental services sector. While the current National Housing Strategy includes a national target of 2,400 new affordable units for people who have a developmental disability, a more ambitious target is required to meet existing need.
- Accelerate the developmental service sector's focus on distributed (as opposed to congregated) models of support and care for people in their communities. As housing options become increasingly distributed throughout the community, so must services and supports.
- Ensure that all investments in new housing options include a focus on and participation of communities experiencing racialization and marginalization, including but not limited to Black, Indigenous and People of Colour.
- Ensure that all new housing developments meet or exceed the requirements of the Accessibility for Ontarians with Disabilities Act regarding universal design. Further – and as the Onley Report noted – a significant investment is required to retrofit existing buildings to be accessible to people who use mobility aids.
- Invest in innovations in specialized, non-congregated community housing options for people with high support needs, people who exhibit destructive or self-injurious behaviour, people with mental health co-diagnoses, and older people who have an intellectual disability (with a focus on aging in place).
- Create a permanent developmental services housing planning table, including representatives from MAH, MCCSS, People First of Ontario, the Provincial Network on Developmental Services, the Canadian Housing and Renewal Association, and the Association of Municipalities Ontario, to help ensure a consistent and streamlined approach to one of the province's most challenging issues.

## A note on resources and funding

The Ontario government spent more than \$2.7 billion on developmental services in 2019-20;<sup>1</sup> the November 2020 provincial budget announced that this amount will grow to more than \$3 billion in 2021-22.

Approximately 25,000 people access residential and/or support services thanks to this funding, and 53,000 receive at least \$5,000 in annual Passport funding. The majority of funds flow to more than 300 transfer payment agencies, many of whom in turn work with an unknown number of organizations known as Outside Paid Resources.<sup>2</sup>

### As of 2019-2020:

 **63,500**  
adults who have developmental disabilities had applied for and were considered eligible for supportive services.

 **20,480**  
of those waiting were receiving no services at all.

 **34,159**  
people were waiting for at least one agency service.

 Just **11,400**  
people were receiving all of the eligible services they had requested.

As both the Auditor General and MCCSS<sup>3</sup> have recently pointed out, little information exists on the average per-person costs of developmental services in Ontario. Access to programs and resources is uneven across regions and organizations, and people with similar levels of need cannot expect similar levels of service. The Auditor General has identified significant issues with agency reporting of even basic information such as the number of people served.<sup>4</sup>

Without comprehensive, accurate and publicly available data on the province's developmental service system, it is difficult to make recommendations about resources and funding of the sector. However, there is clearly a major gap between the resources that are available on one hand, and the level of need in the province on the other.

We believe that this report's focus on greater individualization, de-congregation and attention to natural supports point a positive way forward for both quality of life and cost with respect to people who have intellectual disabilities. We address the issue of cost throughout the report.

## United Nations convention on the rights of persons with disabilities\*

### Article 19 – Living independently and being included in the community

“States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

\* Ratified by Canada in 2010





# We have made progress, but barriers remain

## Summary

Ontario has a positive recent history of increasing support for real inclusion and the attainment of typical lives in the community for people who have an intellectual disability. However, Ontario is lagging other jurisdictions that have found innovative ways to support people to achieve greater independence and well-being.

### 1. Setting the stage: a recent history of righting wrongs

On December 9, 2013, Premier of Ontario Kathleen Wynne apologized to former residents of the province's regional centres for people who have a developmental disability. In her apology, the Premier noted that residents and their families "were deeply harmed and continue to bear the scars and the consequences of this time. Their humanity was undermined; they were separated from their families and robbed of their potential, their comfort, safety and their dignity."

The Premier recounted that regional centre residents "were forcibly restrained, left in unbearable seclusion, exploited for their labour and crowded into unsanitary dormitories. While the model of care carried out by this institution is now acknowledged to have been deeply flawed, there were also cases of unchecked physical and emotional abuse by some staff and residents."<sup>5</sup>

People who lived in the regional centres were segregated and isolated from their families and from the broader community. Our most trusted citizens – doctors, nurses, psychiatrists, religious leaders and others – treated residents as less-than-human. The people forced to live in these institutions were severely neglected, and subjected to repeated physical, emotional and sexual abuse.

In the wake of this recent history, People First of Canada has provided a way forward that moves away from institutions, programs and policies that congregate people labelled as having an intellectual disability:

“An institution is any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.”

“People First of Canada believes that people should exercise their right to voice and choice in choosing where they live and with whom they live. We believe that all people can live within their community, with appropriate supports. We believe that no person, regardless of disability, should live in any kind of situation where they are kept apart from the community.”<sup>6</sup>

This guidance has been adopted by Community Living Ontario and many other organizations in Canada and around the world.



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## 2. Ontario has a strong history of progress in recognizing the rights and freedoms of people who have an intellectual disability

In Ontario, we have a positive history of incremental progress toward the People First vision of increasing support for real inclusion and the attainment of typical lives in the community. For example:

### > 1974

The 1974 Developmental Services Act laid the groundwork for closing the regional centres, supporting people to enter the broader community, and making direct funding available to people and families on a limited scale.

### > 1982

In 1982, Special Services at Home was established to provide funding to families to purchase and control supports for their children – expanding in 1990 to include adults as well.

### > 1980s-90s

Throughout the 1980s and 1990s, regional centres were progressively shut down, and were finally closed for good in 2009.

### > 2008

In 2008, the Legislative Assembly of Ontario passed the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, which was “created to give people with a developmental disability more independence and choice,” and to support people to “participate fully in community life and feel that they truly belong.”<sup>7</sup>

### > 2014

In 2014, the Select Committee on Developmental Services (co-chaired by the Hon. Christine Elliott and the Hon. Laura Albanese) acknowledged the UN Convention on the Rights of Persons with Disabilities, and made recommendations to “empower individuals, families, and communities by providing them with more flexibility to create individualized, culturally and linguistically appropriate, and community-based solutions.”<sup>8</sup>

### > 2017

Since 2017, all eligible adults who have a developmental disability receive a minimum of \$5,000 per year in Passport funding, allowing them to take more control over some of the supports and services they need to live a full life.<sup>9</sup>

### > 2018

In 2018, the Ontario Developmental Services Housing Task Force utilized provincial funding to support 18 demonstration projects piloting innovative housing solutions, with all 18 sites centred on providing supports to people outside of congregated living facilities.<sup>10</sup>



## A – We have made progress, but barriers remain >

We have seen similar progress across Canada as well as in the United States, where there has been widespread and growing support for typical lives in community. For example:

- Between 1977 and 2016, the number of people living in state-run institutions and privately-run Intermediate Care Facilities in the US dropped from 362,000 to 75,000 – a 79% decrease.<sup>11</sup>
- In 1992, about 5,000 people with a developmental disability lived in their own home in the US; by 2010 this number had grown to 127,000 people.<sup>12</sup>
- In 2016, there were 514,000 people with intellectual or developmental disabilities receiving Medicaid support and not living with a family member. Within this population:
  - **56%** lived in settings occupied by 1-3 people;
  - **26%** lived in settings shared by 4-6 people;
  - **10%** lived in settings shared by 7-15 people;
  - **8%** lived in settings shared by 16 or more people – down from 12% in 2010, and from 84% in 1977.<sup>13</sup>

These trends are of course not limited to North America, with connected movements occurring in many jurisdictions. These movements are characterized by a consistent path toward increasing control and community belonging among people who come under the purview of developmental services.

“Many who seek social inclusion in the lives of people with disabilities assume a common understanding about what this means and what the goals are; they commonly speak about ‘ordinary lives’ and community living. In practice, the term has been co-opted. This is seen in a not unusual example of a service that groups people with disabilities, takes them in a service-owned bus to a centre-based programme and refers to this as an inclusion programme because it is located in the community. This practice

is in contrast to a service that supports individuals to pursue ordinary activities with non-disabled citizens, which also refers to its programme as inclusion.”<sup>14</sup>



### 3. “Are We There Yet?” – barriers to real inclusion and typical lives still remain

Developmental service policy and practice have evolved in tandem over several decades. This is a widespread effort that combines person-centred planning, de-congregation, and a recognition that all people labelled as having an intellectual disability “enjoy legal capacity on an equal basis with others in all aspects of life.”<sup>15</sup>

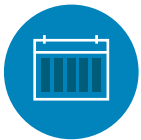
Despite the province’s advances, many people who have an intellectual disability do not in fact experience equal recognition before the law, or equal participation in their communities. Many of those in this population:



**Do not have access to the services and supports** they need to achieve a basic standard of living.



Have **little choice** as to where and with **whom they live, and with whom they will spend their time.**



Have **highly regimented and scheduled lives**, with others deciding when they will wake up, use the toilet, eat, go outside (if they are supported to go outside every day) and go to bed.



**Live in conditions that cause them emotional stress and lead to distressed behaviours**, which then often leads to the non-consensual use of physical and/or chemical restraints.



Are at **high risk** of pervasive loneliness and a range of negative physical and mental health outcomes.

The COVID-19 pandemic has brought new light to the fact that many people supported by the province’s developmental service system continue to lead institutional lives. Across North America, outbreaks of the SARS COV-2 virus have been elevated in congregated settings; the troubling case of Participation House in Markham is just one example.<sup>16</sup>

Efforts to limit the spread of COVID-19 have added to already restrictive policies related to residents’ ability to leave facilities and be with friends and family. People living in congregated settings are, under the terms of their support agreements, always subject to legislated control by the people paid to support them.

On the other side of the coin, people and family members who depended on agency-run day activities for social engagement and respite have found themselves suddenly without options. While those in residential care settings have experienced reduced or completely interrupted contact with family and friends, those outside of it have lost agency supports that are crucial to positive family functioning and the prevention of caregiver burnout.

Everyone in Ontario has been affected by the COVID-19 pandemic, and people who have an intellectual disability more so than most. It is impossible not to wonder how things may have been different if people who have an intellectual disability were supported to live more independently, to build their social networks, and to rely less on paid staff and bureaucratic systems.

The three sections that follow will show that this type of change is possible. This discussion paper will show that Ontario is lagging behind other jurisdictions where people who have an intellectual disability have been better prepared to weather disruptive events like

the COVID-19 pandemic; that it possible for people to have more control, freedom and choice in their lives; that people can live in ways that require less bureaucratic oversight and government intervention; and that people will be healthier and happier as a result.

## A note on disability, race, and research

Unfortunately, very little up-to-date information exists with respect to disability and race in Ontario, or in Canada more broadly. For example, while the Statistics Canada Survey on Disability (CSD) is linked to the Canadian census (which collects information on respondents' 'ethnic or cultural origins'), no reports flowing from the CSD mention race or ethnicity.<sup>17</sup>

In Ontario, publicly available information about people who have applied for developmental service funding is in general very limited. To our knowledge, no information relevant to race, or ethnic or cultural background, has been published for this population. Neither the 2014 nor 2020 Auditor General reports (which contain information that is crucial in understanding the sector) mention race.

Without accurate and up-to-date data, it is impossible to make specific recommendations that take into account the added barriers faced by, for example, Black and Indigenous people who have intellectual disabilities. There is an urgent need for research and published data on people who have intellectual disabilities in Ontario, and particularly data on race.







# B Expanding direct funding to increase choice and control

## Summary

Many jurisdictions around the world have made direct funding a central part of their developmental service systems. For example, all western Canadian provinces, 42 US states, and the United Kingdom offer direct funding as a choice for people supported. This approach has been decisively shown to contribute to higher quality of life and user satisfaction. People who choose this option consistently say they prefer it over traditional supports, despite the increased effort that is required to source and manage services.

### 1. Ontario has fallen behind on direct funding for developmental services and supports

*Direct funding* is the process by which government funds are provided directly to a person or their family (often with assistance from a developmental service agency) to pay for needed services.

The Individualized Funding Coalition of Ontario has stated that:

“all people should have control over decisions concerning where they live, with whom they live, with whom they associate and how they spend their lives. In order to achieve this we recognize that Ontario must develop a system of funding whereby the person requiring assistance, supported by family and/or others, should have access to and control over the funds allocated for [their] supports.”<sup>18</sup>

Ontario has a long history of advocacy for direct and individualized funding<sup>19</sup> as opposed to agency-managed care, which has been characterized by a lack of control over the type and timing of needed supports, a lack of choice as to the people who provide support, and limited ability to improve substandard care. While many excellent agency programs exist, the supports and services that are available to many people who have an intellectual disability are too often of the “take it or leave it” variety.<sup>20</sup>

A leading Canadian direct funding expert summarizes the philosophy of the approach as follows:

“Research on the delivery mechanisms for services and supports has generally supported policy and practice goals towards greater independence, favouring funding attached to individuals as opposed to services. The overarching rationale is that block funded services tend to cater to the interests of systems and agencies as opposed to the interests of meeting individual needs. This is consistent with a rights-based approach to disability, where individuals receive the supports

and services that enable inclusion and citizenship in society, rather than emphasizing collective approaches to caregiving and protection for people with disabilities.”<sup>21</sup>

A recent international review of 73 studies of individualized/direct funding found that the approach contributes to higher quality of life, user satisfaction and – crucially – safety. Direct funding recipients report higher self-image and self-belief, as well as improved community integration. Overall, people preferred direct funding over traditional supports, despite significant issues with program bureaucracy.<sup>22</sup>

Since the introduction of Special Services at Home (SSAH) in Ontario in 1982, the effectiveness of direct funding as a mechanism for purchasing needed supports has been demonstrated repeatedly. Despite this, direct funding for people who have an intellectual disability continues to be very limited. Unlike in several other provinces, it is rarely possible for individuals and their families in Ontario to control and direct the full range of supports and services they need.

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## Direct funding in Ontario

Approximately fifteen percent of Ontario's adult developmental services budget is allocated to a limited form of direct funding (i.e., Passport), with the balance flowing to transfer payment agencies. In 2020 there were approximately 53,000 people accessing Passport funding, and overall funding for the program reached \$434 million.<sup>23</sup> More than \$2.7 billion was spent overall in 2019-2020 to support adult developmental services.<sup>24</sup>

Experience in other jurisdictions (discussed in detail below) shows conclusively that people and families can effectively manage funds for the full proportion of the supports they need (often with assistance from other organizations). Unfortunately, current policy in Ontario makes this impossible:



- Special Services at Home funding is limited to a maximum of \$10,000 per year;
- Passport funding is limited to a maximum of about \$42,000 per year, with very few individuals eligible for the maximum;
- Both Passport and SSAH are subject to limitations in use, and are insufficient to cover the full support and community participation needs of most eligible people;
- While governing legislation contains provisions for the direct funding of a full range of residential and community supports, these provisions will not come into force until 2023.<sup>25</sup>



Several jurisdictions have gone much further with direct funding as a comprehensive option alongside agency-managed supports. The following examples can be instructive in the design of a made-in-Ontario expansion of this type of funding.



## The developmental service workforce in ontario

Developmental service agencies in Ontario rely heavily on a workforce of Developmental Service Workers, Adult Protective Service Workers, and Personal Support Workers. Numerous studies have described the high demand and relatively low pay for PSWs specifically, and for front line social service professions more generally.<sup>26</sup>

The cost of front line DSWs, APSWs and PSWs is a crucial element of developmental service expenditures. The DS sector has traditionally struggled to compete against the compensation levels offered in health care, and increasingly the same is true with respect to long-term care, where recruitment is now a top priority.

One of this report's recommendations concerns the establishment of minimum rates of pay for DSWs, APSWs and PSWs, including coverage of group health benefits, liability insurance and membership in relevant professional bodies. This is essential if we are to ensure an adequate, skilled and professional workforce to support people who have developmental disabilities. While it creates additional cost pressures, it has vital implications for the health and well-being of a workforce that is disproportionately composed of women, recent immigrants, and Black, Indigenous and People of Colour.





## 2. Direct funding has expanded with positive results in other jurisdictions

### Direct payments and personal budgets in the United Kingdom

In the United Kingdom, anyone eligible for state support for ‘adult social care’ (including seniors, people who have an intellectual disability, and people with mental health issues) has a right to ask for direct payments, rather than opting for support arranged by their local government.<sup>27</sup> People can also access a combination of direct payments and state-funded agency supports. Other elements of the UK system include the following:

- Payments can be made directly to an eligible person, to a family member, or to another person appointed to manage relevant funds;
- In some cases, relatives can be employed as caregivers;
- Recipients must keep records and account for how direct payments are used;
- Direct payments are not counted as income for tax purposes;
- If independent support workers (i.e., those not employed by an agency) are hired, recipients take on the role of employer and are responsible for statutory employment-related costs, liability insurance, etc.<sup>28</sup> A number of organizations offer assistance to manage these requirements.<sup>29</sup>

To address commonly held concerns about the potential cost of direct payments, UK policy holds that “a local authority should not make direct payments unless they are at least as cost-effective as the services which it would otherwise arrange.”<sup>30</sup>

Further, the high degree of attention to reducing spending in the UK over the past several decades has spurred a number of studies comparing direct funding to agency-provided services. These studies have been summarized as demonstrating that “direct payments are more cost-effective than directly-provided services and, in some studies, may sometimes even be cheaper.”<sup>31</sup> Additionally:

“... direct payments have consistently been shown to be a cost-effective mechanism for enabling disabled people to access high-quality support that maximizes choice and control at equivalent or, often, lower cost than other forms of community-based support.”

...“The most detailed study carried out in the UK, for example, showed that support packages based on direct payments were on average 30%-40% cheaper than equivalent directly provided services. This study also highlighted very clearly that people receiving direct or indirect payments had higher overall levels of satisfaction with their support arrangements.”<sup>32</sup>

In 2013-14, 170,000 people in England, Scotland, Wales and Northern Ireland (accounting for 24% of eligible seniors, people who have an intellectual disability, and people with mental health issues) took advantage of direct payments for all or part of their publicly-funded supports. A key contributor to program uptake was the availability of services to assist people and families to take on the role of employer, identify service providers and maintain adequate records.<sup>33</sup>

More than 500,000 people in the UK (including people who have an intellectual disability) make use of *personal budgets*, which in many ways form the basis of adult social care in the country.<sup>34</sup> Personal budgets set out the annual cost of the supports and services that people require, and transparently identify the proportion of costs to be covered by the state versus how much must be contributed (where possible) by people themselves:

“... a personal budget involves being clear with the person at the start how much money is available to meet their needs, then allowing them maximum choice over how

this money is spent on their behalf and over how much control they want over the money itself... the key is that the person knows immediately how much is likely to be spent on their needs, and can then be more creative in thinking of new ways to meet these needs.”<sup>35</sup>

All people who have an intellectual disability in the UK – including those who live in state-supported group homes – have a right to a personal budget. A recent report of the UK National Audit Office found that:

“... most users, but not all, report benefits when services are commissioned through personal budgets, particularly direct payments. However, if a personal budget is put in place without adequate support and information, and without being aligned to a user’s circumstances, it may not benefit the user. This can occur if authorities are pursuing personal budgets as an end in themselves, rather than as an enabler of personalised care.”<sup>36</sup>



... direct payments have consistently been shown to be a cost-effective mechanism for enabling disabled people to access high-quality support that maximizes choice and control at equivalent or, often, lower cost than other forms of community-based support.



## Could personal budgets work in Ontario?

Currently, funding for developmental services in Ontario largely flows in block payments to more than 300 transfer payment agencies. These agencies are then responsible to use their annual allocations to provide housing, support and care to the people for whom they are accountable.

Annual allocations are largely based on previous years' funding levels, rather than (for example) the exact number people served or the overall weighted support needs of an agency's client base. While this has provided some impetus for organizations to offer support and care in flexible and innovative ways, it also has drawbacks. For example, people with similar levels of need can receive substantially different levels of support depending on their location. Organizations with a declining client base may see per-person revenues increase, while those with static or increasing client numbers are forced to counter increasing input costs (e.g., food, staffing, insurance, etc.) by reducing levels of care.

*The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* contains a yet-to-be-enacted provision for a funding body that would “develop a service and support profile for each applicant who is



determined to be eligible for services and supports” from the developmental service sector.<sup>37</sup> A person's service and support profile would include the amount of funding available – in other words, a personal budget.

To prepare for the province's move to personal budgets, it is crucial to initiate research into current per-person costs in agencies across the province. Only with this data will the provincial government be in a position to understand the larger cost implications of personal budgets for all people supported by developmental services.

## Direct payments in the United States

As of 2018, forty-two US states make direct funding (often referred to as ‘self-directed supports’) widely available to people who have an intellectual disability.<sup>38</sup> Direct funding in the US mirrors the experience in other jurisdictions: a beneficial program that seems to appeal to a minority of service users. Of the forty-two states where this type of funding is available, fifteen report that at least ten percent of those eligible are in fact accessing it.<sup>39</sup> Across states, 12% of all supported individuals have chosen the direct funding option.<sup>40</sup>

Following are a few examples of self-directed support programs in the US:

- **New York State’s Self-Directed Services** initiative allows for direct funding of some or all funded services for eligible people. Participating individuals are required to develop a Circle of Support composed of people they choose (including family, friends and staff), and can hire brokers to assist with administration.<sup>41</sup> Nearly 13,000 adults current take advantage of the program.<sup>42</sup>
- **Oregon’s K Plan** is one element of the state’s actions to increase the availability of home-based services for a number of groups, including adults and children who have developmental disabilities. The program is directed at people “who want to stay in their home community and remain independent, healthy and safe. At the same time, it saves both the state and federal government money because we are providing more extensive home and community-based, long-term services and supports in lieu of more expensive institutional care.”<sup>43</sup> More than 26,000 people are enrolled in the initiative.<sup>44</sup>
- **Pennsylvania’s Person/Family Directed Support Waiver program** allows people with lower support needs (capped at \$33,000 per year for support services, and an additional \$15,000 for employment services) to choose self-directed or agency-managed supports to live independently in the community. All people participating in the program must be informed about self-directed options by service providers, and all those who live in a private home must be offered the option of direct funding.<sup>45</sup>

For people with higher support needs and severe functional limitations, the Pennsylvania OBRA waiver program provides higher levels of assistance to individuals and families. The state’s policy on self-direction is instructive:

“All participants... have the right to make decisions about and self-direct their own waiver services and may choose to hire and manage staff using Employer Authority. Under Employer Authority, the participant serves as the common-law employer and is responsible for hiring, firing, training, supervising, and scheduling their support workers. In addition, participants may choose a combination of service models to meet their individual needs. Participants are encouraged to self-direct their services to the highest degree possible.”<sup>46</sup>



- Washington State’s Community First Choice program<sup>47,48</sup> offers access to attendant care, skills training to support greater independence, assistive technology, service planning and coordination, caregiver management training, and a number of other services. Participants can choose self-directed or agency-managed options, and nearly 40,000 people have chosen to self-direct.<sup>49</sup>

### Australia’s National Disability Insurance Scheme

In Australia, much has been made of the negative aspects of the National Disability Insurance Scheme (NDIS) launched in 2016.<sup>50</sup> However, the history of the Australian approach is instructive, as it replaced a disability service regime that in many ways mirrored the system that currently exists in Ontario.

Before the NDIS was implemented, disability-related supports in Australia were:

- Largely block-funded, with transfer payments directed to service providers who were overburdened by policy restrictions that suppressed innovation;
- Focused on addressing crisis situations, rather than early intervention;
- Triaged and rationed so that only a portion of people in need were supported;
- Complex and confusing for end users, with little personalization or flexibility.<sup>51</sup>

These criticisms are remarkably similar to those made by the provincial Ombudsman in his 2016 report on Ontario’s developmental service system.<sup>52</sup>

During its development, the NDIS – which is essentially a direct-funding program on a massive scale, incorporating people who have a disability of all ages – was broadly supported. Four years into the program’s implementation, People with Disability Australia (PWDA) has expressed a “strong and continuing support for the objects and principles” of the NDIS. Further, PWDA holds that “the vision for the NDIS still stands as a way of introducing a national, universal system to replace the old, broken and unfair system of past provisions of disability services.”<sup>53</sup>

The implementation of the NDIS was a momentous transformation, and any transition of this magnitude risks substantial drawbacks. At the same time, the launch of the NDIS was bolstered by an increase in funding for disability-related services, and this seems to have contributed to increased access to needed supports for many (though not all) participants. It is notable that people who are covered by the NDIS report greater satisfaction with services received, compared to those not covered.<sup>54</sup>

## B – Expanding direct funding to increase choice and control >

The downsides of the NDIS offer an important reminder that disability service system users require ongoing assistance with understanding, navigating and advocating within such a system. PWDA has stated that:

“There is an emerging and troubling picture that some people get good plans while others, particularly from marginalized groups or communities are left with poor quality plans, with limited access to supports and services.”<sup>55</sup>

This criticism was also made in an arm’s length evaluation of the scheme, noting that:

“While in general the NDIS is leading to increased levels and quality of services and support, not all people with disability have experienced improved outcomes under the NDIS. People with disability who are unable to advocate for themselves or who struggle to navigate NDIS processes are at risk of receiving lower levels of services than previously, and many have.”<sup>56</sup>

In the same review, NDIS staff reported that “participants and families who were confident, educated and able to articulate support needs had better outcomes than those with less capacity to understand the NDIS, including participants with intellectual disability.”<sup>57</sup>

The NDIS is currently overwhelmed by a level of demand that far outstrips what providers can supply, with long wait times and a shortage of quality service agencies contributing to this issue. It is crucial to note that NDIS participants who have an intellectual disability have had the most difficulty finding services for which they had funding, and report significant unmet demand.<sup>58</sup>

The implementation of the NDIS has represented a sea change for service providers, which include both non-profit and for-profit organizations. According to a recent report published by National Disability Services, between 20% and 30% of organizations participating in the NDIS reported a loss/deficit in each year from 2016 to 2019. There are ongoing concerns about the pricing of services and the ability of providers to offer quality services with current funding levels.<sup>59</sup>

## Direct Funding in Western Canada

Every province to the west of Ontario has a substantial history of direct funding for people who have an intellectual disability.

### BC

In **British Columbia**, any adult eligible to receive funding via the Community Living BC (CLBC) crown corporation may access the province's Individualized Funding program. Anyone receiving more than \$6,600 must have a representation agreement that identifies an 'agent' with legal authority to act on the person's behalf.<sup>60</sup> People are eligible for the same amount of funding to which they would have access through a service agency, with funding levels based on need, the estimated cost of supports, and available funding.<sup>61</sup> It is possible for people – in many cases assisted by family members or other representatives – to manage their own finances, develop a microboard, or work with a Host Agency that manages funds in consultation with them.<sup>62, 63</sup>

As of 2019, 1,152 people accessed some form of direct funding in the province, accounting for 6% of people receiving support through CLBC.<sup>64</sup>

BC is well known for its development and use of microboards – groups of at least five people that join together with a person who has an intellectual disability to form a non-profit society. The society then assists the individual to create a life plan, advocate for what they need, and manage funds and services.<sup>65</sup>

Microboards are involved in about 20% of individualized funding relationships with CLBC; direct-funded respite accounts for the majority (65%) of cases, with direct (non-microboard) and host agency funding making up the remaining 15%.<sup>66</sup>

The BC system of individualized funding is likely the most well-researched and evaluated in Canada. In line with other studies of the approach around the world, a 2013 UBC-based inquiry concluded that “individualized funding methods can cover virtually all services supported by Community Living British Columbia, at a cost relatively equal to or lower than traditional block funded services.”<sup>67</sup>

### AB

In **Alberta**, the Family Managed Services (FMS) program was launched in 2006, and “allows for an individual, their family or a person close to the individual to manage the delivery of services... by hiring staff directly or by obtaining supports through a Persons with Developmental Disabilities (PDD) approved service provider.”<sup>68</sup> The program built on decades of below-the-radar direct funding to families of people who have a developmental disability beginning in the 1970s.<sup>69</sup>

Family Managed Services (FMS) funds are most often administered by family members; however, it is also possible for non-family members of an individual's close personal network to take responsibility for administration. As in many other direct funding programs, these individuals take on a significant degree of responsibility for the prudent use of funds. This can include acting as an employer if services are not purchased from an approved service provider, and developing and maintaining an Individual Support Plan.<sup>70</sup> Despite this, use of the program grew by 132% between 2010 and 2018, and approximately 10% of people (about 1,200 people) supported by the PDD program access FMS.<sup>71, 72</sup>

Alberta has developed a substantial infrastructure to support direct funding. The province provides a broad set of resources that balance a freedom to innovate with the need for monitoring. For example, the provision for three-year contracts allows people and families to plan predictable and consistent long-term support. The administrative process incorporates a consistent government oversight role – without the bureaucratic micromanagement that can bog down agency care – and resources to address safety concerns.<sup>73</sup>

It is notable that FMS is available to people who have 'complex service needs,' defined as individuals "who pose a significant risk, and/or are destructive to themselves, others, or property," and who may have had organizations refuse to provide services because of such behaviour. There is a clear recognition of the need for specialized supports in such cases, and a willingness to work with people and families over the long run.<sup>74</sup>

## SK

In **Saskatchewan**, self-directed funding has been available to people who have an intellectual disability since 2017.<sup>75</sup> The program was built on lessons learned from programs in BC, Alberta and Manitoba, as well as a comprehensive and insightful pilot study in Saskatchewan.<sup>76</sup> People can choose to receive direct funding for residential and day supports, i.e. assistance with personal care, employment, volunteering, etc.<sup>77</sup> People receive the same amount of funds that they would be able to access if they opted for a traditional agency model of funding.<sup>78</sup>

## MB

In **Manitoba**, most families with children receiving support from the province's Community Living disABILITY program do so via direct funding, with nearly 2,000 families in this situation. Additionally, about 20% of adults who have an intellectual disability living outside of group homes (more than 220 people in total) direct and pay for their own supports.<sup>79</sup> The province's Department of Families also supports *In the Company of Friends* (ICOF), a longstanding direct funding program managed by the organization Innovative Life Options. As of 2016, 65 people received funding through the program. To qualify, people must show that they have a strong support network (which can include both family and friends in an unpaid capacity) that has agreed to assist them when necessary to self-manage day-to-day living tasks. ICOF participants hire and supervise their own staff, and decide how they spend their time and money.<sup>80</sup>



### 3. Moving forward with expanded direct funding in Ontario

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People who have an intellectual disability and their families have been calling for a comprehensive direct funding option in Ontario since the 1980s; it is time to make it a reality.

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The provincial government can build on lessons learned in Canada and around the world to design a fiscally prudent system that is responsive to those who wish to access it.

Based on evidence from existing programs as described above, Community Living Ontario recommends the following:

- ✔ Offer a direct funding option to all adults who are eligible for developmental service funding through the Ministry of Children, Community and Social Services, regardless of the level of assessed need for services and supports.
- ✔ Make direct funding available via “Expanded Passport,” a new program that fits within the existing Passport infrastructure, with the following key changes:
  - Funded services and supports will be expanded to include all items available via block-funded agency agreements and the existing Passport program. The cost of services and supports set out in annual plans must be equal to or lower than those provided via block-funded agency agreements.
- ✔ Plan managers (i.e., people themselves, family members or close personal friends, or transfer payment agencies) will be approved using clear and transparent guidelines, and will develop and submit annual individualized plans with clear goals and outcomes. Plans must address:
  - i. A detailed outline of services and supports that will be purchased from agencies and/or individuals (including planning supports),
  - ii. Additional out-of-pocket funds to be contributed by people and family members (note that these should not lead to reductions in program funds), and
  - iii. The role of in-kind and unpaid supports from personal support networks (often referred to as ‘natural supports’).

It is highly recommended that more intensive plans (e.g., requiring more than \$50,000 in program funds) require the engagement of facilitation and management support.

## B – Expanding direct funding to increase choice and control >

- Advance funding will be made available on a quarterly basis, with a requirement for regular financial reporting to the funding/oversight agency.
- Abuse prevention and reporting will be a key focus, particularly in the planning and approval stages, with (at minimum) annual meetings required between plan managers, the people accessing supports, and funding/oversight agency representatives.
- ✔ To support fairness across employment situations, minimum rates for the payment of Personal Support Workers and other staff will need to be established. Funding levels must account for inflation, coverage of group health benefits, liability insurance and membership in relevant professional bodies.
- ✔ Initiate research to understand the real per-person costs of developmental services in a representative sample of transfer payment agencies and Outside Paid Resource organizations, in preparation for the coming-into-force of the new “funding entities” described in section 18 of the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*.
- ✔ Implement pilot projects that develop personal budgets for at least 100 people currently supported by a transfer payment agency and/or Outside Paid Resource. Ensure the involvement of the individuals supported, family members and other supporters, and independent facilitators where available.

# C Transforming Ontario's day programs for adults who have an intellectual disability

## Summary

The COVID-19 pandemic led to widespread closures of congregate day programs for people who have an intellectual disability. Developmental service agencies were forced to innovate and create new, more individualized day supports that depended heavily on virtual outreach and engagement. Looking to the future, organizations are searching for ways to keep this focus on individualization. Many agencies around the world offer a template for moving forward in this vein.

## 1. Introduction

Direct funding and a movement away from housing congregation (discussed in the next section) are two key avenues for increased individualization and choice for people who have an intellectual disability. While not a panacea, they have been proven to result in greater belonging and typical lives in the broader community.

An important third pillar of a typical life centres on what people do during the day. Not long ago, thousands of Ontarians labelled

as having an intellectual disability spent their days in sheltered workshops, where they performed basic tasks like paper sorting and box packing for minimal compensation (i.e., less than \$2 per hour).<sup>81</sup> In response to the announcement that these workshops would be prohibited as of January 2019 (a change that was subsequently delayed by the current provincial government), many operators wound them down and transitioned to group day activities focused on hobbies, social engagement, and community outings.

## 2. The problem with congregate day programs

As tends to be the case with group homes and block funding, group day services “emphasize specific settings of care and providers without always recognizing the input or preferences of the individual.”<sup>82</sup> A growing alternative to this model is a de-congregated approach that treats “a person as a multifaceted individual rather than the carrier of a particular symptom or illness” and hinges on a partnership between service provider and participant, with shared power and decision making.<sup>83</sup>

Article 19 of the Convention on the Rights of Persons with Disabilities, ratified by Canada in 2010, directs us to ensure that “persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.”

Congregate day programs are a clear example of segregation from the broader community. In the wake of pervasive closures of such programs as a safety measure during the COVID-19 pandemic, many organizations are actively considering keeping them closed for good and moving to individualized supports – in other words, programs that respond directly to the personal interests of participants via engagement with non-developmental sector recreation, voluntary, employment and other stakeholders. They expand beyond the traditional 9:00 to 3:00 day program window, and support people to develop natural circles of friendship and support.



Article 19 of the Convention on the Rights of Persons with Disabilities, ratified by Canada in 2010, directs us to ensure that “persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.





### 3. Balancing safety, risk and lives worth living

There are two sides to the story of day programs, with different perspectives characterized by opposing approaches to risk. One perspective stresses the safety, security and predictability of the traditional day program – a service that working families and service providers can depend on to watch over labelled people and control their sometimes challenging ‘behaviours’ in a way that is widely considered to be cost-effective. The following quote from an Australian developmental service CEO describes this type of program:

“When I became CEO in mid-2008, Amicus looked like most other day services in that we operated Monday to Friday, 9am to 3pm, with six weeks of leave each year and most of our support occurred in a facility base. We had a menu of activities that people choose from each year that were really based on filling peoples’ days and allowing them to socialise with other people with a disability. Even the limited community supports involved people starting at the facility in the morning and travelling back for a long lunch then back into the community prior to travelling back for a 3pm pick up to go home.”

– **Ann-Maree David**, CEO, Amicus<sup>84</sup>

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The outings that are typical of day programs are sometimes referred to as *community tourism*: the stigmatizing group trips where people labelled as having an intellectual disability move as a group within and around people not so labelled, monitored by staff, often with only the stares of onlookers serving as a connection between the two socially constructed sides.

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The opposing perspective on day programs has a more ambivalent relationship to risk. Very simply, it holds that there is no real and fulfilling life without risk. Community living is about maximizing independence, choice, control and typicality – and risk is inseparable from these things. Further, if we look closely at developmental service organizations that have embraced the risks and realities of average and typical lives, the perceived benefits of the traditional day program model – i.e., safety and cost-effectiveness – turn out to be illusory (more on this below).

## 4. The link between day programs and ‘challenging behaviours’

“Some care environments increase the likelihood of behaviour that challenges. This includes those with limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise. It also includes care environments that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse, and those where physical health needs and pain go unrecognised or are not managed.”<sup>85</sup>

Among organizations that have closed their congregate day programs and moved to individualized supports, there is a consistent theme of staff reporting that challenging client behaviours – which are to a large degree a response to a lack of personal control and choice<sup>86</sup> – reduce or disappear entirely. Without these distressed behaviours, and with attention to the development of natural supports, the high levels of monitoring and control by paid staff are not needed by a large number of clients.

It is not surprising that, as people gain control over their lives and gain the ability to do the things they want to do – rather than having their movements and activities prescribed and controlled for much of each day – they become happier and quite substantially less angry and prone to acting out. And without distressed behaviours or a high need for monitoring, the perceived cost advantage of congregate care disappears, as the following quotes from four organizations across four countries highlight:<sup>87</sup>



“The first eight weeks of the new [non-congregate] service were characterised by... the complete absence of behavioural problems [and] the positive impact of increased physical activity on clients’ moods and functioning.”

– **Avalon (BOP) Inc.**, New Zealand

“... a significant reduction in incidents as we were able to totally avoid the whole large facility-based chaos and time spent waiting at the beginning, middle and end of the day.”

– **Amicus**, Australia

“... [There was one] client who had two full-time staff during waking hours and an active staff member overnight. Using the service approach at Amicus, she has been introduced to more community experiences and increased her independence until she is now receiving only 5 hours of support each day.”

– **Amicus**, Australia

“More generally, declining costs result from a less over-protective orientation to risk management and a diminishing tolerance for squandering resource on our part.”

– **Muiriosa Foundation**, Ireland

“It is not uncommon for people to need less paid support over time, as they expand their networks and build their repertoire of skills and interests.”

– **Spectrum Society**, Canada



There is unfortunately little academic research available on changes in distressed behaviours, and on related administration of sedating medication, when a person moves from congregated and choice-poor settings to more independent and choice-rich living. The literature that does exist provides some support for the many first-hand accounts of frontline professionals, to the effect that

greater individualization and personal control of living situation correlates with fewer distressed behaviours and less use of sedating medication.<sup>88</sup> (It must be noted that there is a substantial and longstanding literature showing that antipsychotics such as risperidone are no better than placebo in preventing distressed behaviours).<sup>89</sup>

## 5. The personal and policy advantages of increased choice and independence

Across the literature related to organizations that have closed congregate day programs and/or group homes and moved to true person-centred planning and supported independent living, there tends to be three common themes:

These three themes are encapsulated in the following quote regarding a client of Community Living Thunder Bay:

“For many years Doug lived in institutions and group living arrangements even though it was apparent he struggled. Rights restrictions and PRN\* protocols were established over the years to help him as he struggled. As his support team spent time reflecting on his needs, interests and what was important to him they anticipated that he might try living in his own home... Since moving into his own place, he has had no need for rights restrictions or PRN medications.”<sup>90</sup>



1

Cost savings or cost neutrality.



2

Reduction of distressed behaviours as people gain control over their lives.



3

The appropriateness of individualization across need levels – including for people who have been the object of very high staff monitoring and involvement.

\* PRN (pro re nata) medications are those that are used “as needed” and include sedating agents used to control people in distress.

We can see a similar perspective in this quote from Community Living Atikokan:

“... we realized that what we perceived as challenging behaviours were likely individuals attempting to tell us they weren’t happy. In fact, the way we were supporting members could actually be the cause of the behaviours. We went back into the files and... began to compile statistics. We were surprised at the trends that emerged. Members had numerous incidents with some staff and none with other staff.”<sup>91</sup>

A growing number of organizations have stopped offering day services in group settings, choosing instead to help connect people to experiences based on their personal interests. The following anecdote offers insight into a fourth theme of the literature tracking this evolution – increasing quality of life and happiness of clients:

“We started exposing people to lots of experiences and people started to let us know which of these experiences they wanted to stick with and which they didn’t. We tried to not only match skills to potential opportunities but potential for success. If someone likes to swear like a trooper, where could they spend time where others might not find this offensive? The woman they had been sitting beside at the workshop, however, who did find it offensive, no longer had to listen to it, and instead started volunteering at a church.”<sup>92</sup>

– **Community Living Upper Ottawa Valley**



... we realized that what we perceived as challenging behaviours were likely individuals attempting to tell us they weren’t happy. In fact, the way we were supporting members could actually be the cause of the behaviours. We went back into the files and... began to compile statistics. We were surprised at the trends that emerged. Members had numerous incidents with some staff and none with other staff.



## 6. Increasing real employment in the community

Employment is a key ingredient in the de-congregation of day supports, and there is a significant infrastructure supporting the non-sheltered employment of people who have developmental disabilities in Ontario. Despite this fact, rates of employment in the population continue to be very low – hovering around 25%, compared to about half among people with other disabilities, and 75% among people who do not have a disability.<sup>93</sup>

Ontario is not alone in experiencing a low rate of employment among people who have an intellectual disability. In the United States, United Kingdom and Australia, for example, employment rates hover around 20%.<sup>94</sup>

As noted above, Ontario was a leader in its plan to close sheltered workshops, though some continue to exist in the wake of the 2018 postponement of related changes to the Employment Standards Act. Many provinces, U.S. states and countries around the world continue to allow both sheltered workshops and the payment of subminimum wages to people labelled as having an intellectual disability – though a number of jurisdictions have moved to end both of these practices.<sup>95</sup>

While open employment for people labelled as having an intellectual disability is still a new frontier, there are a number of positive outcomes associated with it. For example, people who are employed in the open market report higher self-determination, autonomy, and feelings of empowerment.<sup>96</sup>

They also report increased well-being and self-esteem, and growth in skills for daily life including literacy and communication.<sup>97</sup>

At the same time, open employment puts people who have been labelled into direct contact with co-workers and a general public that may hold a range of negative stereotypes about people with visible differences. People with experience in the open job market have reported pervasive differential treatment, including low expectations/not being valued, being passed over for advancement, and both subtle and overt forms of discrimination.<sup>98</sup>

While low labour force participation among people who have an intellectual disability is the norm across high income countries, some jurisdictions have had more success in changing this fact than others. In the United States, for example, Vermont – where the state’s last sheltered workshop was closed in 2004,<sup>99</sup> and no one is paid less than the minimum wage<sup>100</sup> – has consistently seen approximately 40% of residents with developmental disabilities in paid employment in the community,<sup>101</sup> with an average of eight hours per week at about \$12 per hour.<sup>102</sup>

Several northeastern states match the Vermont numbers, with New Hampshire, Maine, Rhode Island and Connecticut showing employment rates above 30%.<sup>103</sup> Of these states, only Connecticut continues to allow sheltered workshops and subminimum wages for people labelled as having an intellectual disability.



In Canada, the national Ready, Willing and Able initiative supported more than 1,200 people with intellectual disabilities or Autism to find employment between April 2015 to June 2017; three-quarters of the jobs generated by the initiative were for 15 or more hours of work per week, with an overall average of 21 hours per week; all offered pay equal to or above the minimum wage, and in the same range as non-disabled co-workers. Employees supported through the initiative earned \$9.6 million in total over the course of its first two years.<sup>104</sup>

The province of British Columbia initiated a concerted effort to increase employment among people who have an intellectual disability in 2013, with the goal of assisting 1,200 people to enter the labour force. Over the course of two years, the proportion of people assisted by Community Living British Columbia (a provincial crown corporation) reporting employment income grew from 15% to 23%; 1,400 people assisted by the organization succeeded in finding employment during this period.<sup>105</sup>

These and other examples show that successful employment in the open market is attainable for people who have an intellectual disability. A Canadian research paper from 2006 states that, “While negative employer attitudes can deter the hiring of people with intellectual disabilities, once contact is established between employers and individuals such attitudinal barriers can be overcome.” The authors go on to outline a number of research-supported learnings and best practices that span several decades:

- 
- > Most employers who have hired people labelled as having an intellectual disability describe the experience as positive;
  - > Most employers are willing to provide needed accommodations;
  - > Successful hiring often hinges on effective mediation services provided by non-disabled service staff; many employers are (unfortunately) uncomfortable with direct initial contact from people with disabilities, and may feel unable to manage perceived risks without assistance;
  - > People in congregated living situations tend to be more highly stigmatized by potential employers;
  - > Despite the need for effective mediation, on-site job coaches often interfere with workplace integration and can be detrimental to job retention;
  - > Workplaces that support relationships across contexts (e.g., those that include interaction outside the workplace), that have interdependent work functions, that offer regular opportunities for non-work interactions (e.g., a shared lunch break), and that are characterized by a team-building management style are more conducive to successful supported employment.<sup>106</sup>
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There is a voluminous literature on what works in supported employment. A wise and strategic investment in this area has the potential to increase well-being among individuals, reduce reliance on congregated day programs, reduce Ontario Disability Support Program expenses, and increase the true community inclusion of people labelled as having an intellectual disability.

## 7. Organizational prerequisites for change

In a July 2020 webinar on person-centred developmental services, Lynne Seagal of Hope House in Norfolk, Virginia talked about “cutting off the branch.”<sup>107</sup> To cut off the branch means to make a decisive change in organizational direction, and to move forward without looking back or revisiting. Helen Brownlie of Avalon (BOP) in New Zealand has framed this perspective as “Don’t look back we are not going that way.”<sup>108</sup>

It is important to note that this does not mean cutting off people’s supports or implementing thoughtless change – in fact, the organizations quoted above delved deeper into the strengths, needs and preferences of those they served in order to connect them to an appropriate combination of paid and natural supports. Support organizations must meet people where they are at; they must work together with each person to create options that are better than what they are being asked them to leave behind. Active listening, collaboration and trust are key ingredients in this transition.

Michael Kendrick has often written of the important role of this type of decisive leadership in the de-congregation of developmental services, including day supports. In a 2009 paper, Kendrick outlined key characteristics of eight closely studied developmental service organizations in the United States that had shifted to individualized service, including the following:

- Values-based leadership was a crucial factor in transformation, with boards of directors a key component. Change was often made in the face of substantial internal controversy and opposition from families and other stakeholders.
- Individualized options were made available to, and group options were (over various time frames) closed off from, the entirety of the client base, regardless of level of need. Despite this, few people elected to move to different providers.
- Individualization took place within the context of larger systems that continued to focus on congregated services.
- There was no expectation that this policy change would be supported by the broader regional social service system. Agency leaders saw themselves as trailblazers operating on principle.
- Transformation was often advanced one person at a time. After policy was changed, staff immediately began to work with each person to create individualized services and supports.
- Most of the agencies viewed families as a valuable resource rather than as “burdened and in need of respite.” A high degree of attention was paid to both (a) natural supports and (b) what the agency could provide.
- All the agencies held that “vision and values for people’s lives were much more important than money as a determinant of good person-centred outcomes.”
- Each agency developed a transparent individual budget for each person supported.<sup>109</sup>

Kendrick also offers a series of guidelines for organizations on the road to individualization. These range from the relatively straightforward – e.g., learning from other successful organizations, outreach to funders and regulatory bodies, making individualization a priority of the board and leadership team –

to the more complex. Examples of the latter include creating a separate and specific body within the organization to lead change efforts, ceasing the expansion of congregate service models as of a fixed date, and actively leaving congregate service spaces unfilled.<sup>110</sup>

## 8. Multiple paths to change

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The histories of organizations that have made the transition from congregated day services to individualized supports show that, while there are important commonalities, there is no single path to change.

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Some organizations, for example, Avalon (BOP) Inc. in New Zealand, have transitioned from top to bottom on a set date, with a holistic new approach and a new set of policies. Others, including the Muiriosa Foundation in Ireland, have identified or created departments within their organization to lead the charge on individualization while other divisions continue on (temporarily) as before. Still others, like the ARC of Rensselaer County in New York, and the Spectrum Society for Community Living in BC, have implemented individualization on a person-by-person basis.

While some transitioning organizations have implemented transparent individualized budgets for each client, others have not taken this step – instead using pooled resources as a source of flexibility during a time of uncertainty and change. And while some have followed

an individualized path since the 1980s, others have only recently transitioned to this model.

One development common to organizations that have made this transition is the unloading of property, including vehicles and buildings that became unnecessary. Another is the fact that transitions have been made for clients who, within congregate settings, had both very low and very high paid support needs. Yet another is the insight that there is value in hiring personal support workers based on values, interests and connections, rather than looking for someone with history in the sector. In fact, many have found value in hiring people with no history of employment in developmental services – and thus no preconceived notions of what is possible. All faced negative feedback from families resistant to and afraid of change.

## 9. Moving forward with individualized day supports in Ontario

In Ontario, we have many home-grown examples of organizations that have evolved away from congregated day programs. We also have a history of transition from sheltered workshops that, once it is made official via legislated change, will put the province in a select group of jurisdictions that have eliminated subminimum wages – an important step in recognizing the rights, capabilities and contributions of people who have an intellectual disability.

The developmental service sector’s response to COVID-19 – particularly agencies’ transition from in-person to virtual adult day supports – shows that transformative evolution is possible. Given the fact that transfer payment agency revenues for day programs flow mainly from provincial block funding, Passport funds and out-of-pocket payments from people and families, there are comparatively few legislative and policy barriers to day program reform.

As we have seen in the examples outlined above, this particular transition is highly dependent on agency-level leadership and resolve. The extent to which system leaders have evolved in spite of broader sector constraints is striking – however, from a policy perspective in Ontario at least, the path to change is open. That being said, there are steps the provincial government can take to spur organizations to make this change:

- ✓ Repeal paragraph 6 of subsection 3(5) of the Ontario Employment Standards Act (i.e., “This Act does not apply with respect to... An individual who performs work in a simulated job or working environment if the primary purpose in placing the individual in the job or environment is his or her rehabilitation.”). This will eliminate the practice of paying employees who have an intellectual disability a pittance, and end once and for all the fiction that people are being rehabilitated or trained in sheltered workshops for years at a time.
- ✓ Make innovation funding available to developmental service agencies who wish to evolve away from congregated adult day supports.
- ✓ Highlight the evolution toward individualized supports for an active life in community as a key element of the province’s forthcoming developmental services reform agenda.
- ✓ Set clear and ambitious targets for the market-based employment of people who have an intellectual disability among Service System Managers, including those currently operating (i.e., in the Hamilton-Niagara, Muskoka-Kawartha and Peel regions) and those slated for future implementation.

# D From institutions, to group homes, to supported independent living

## Summary

Ontario has made great strides in creating quality small-scale residential options for people who have intellectual disabilities. It is crucial that we continue to build on our successes by appropriately moving people into greater independence, and that our expectation is that all people with disabilities can be supported in the community. Research overwhelmingly shows that – with appropriate supports and oversight – smaller scale and more independent residential settings support a higher quality of life at lower cost than larger congregated models.

### 1. The meaning of home

Since the 1970s, there has been a long evolution of housing approaches developed for (and sometimes with) people who have an intellectual disability in high income countries. Today, governments, professional bodies, academics, social service leaders, families, and people themselves broadly agree that large-scale congregate facilities do not support a high quality of life among people who have an intellectual disability.

No one dreams of living in a large building, reminiscent of a hospital, where your movement is monitored and controlled, and where at any moment your privacy, independence and self-direction can be undermined under the terms of your accommodation agreement (e.g., by the use of physical or chemical restraints).



In 2010, the International Association for the Scientific Study of Intellectual Disabilities released an official statement on large congregate facilities:



“The gradual abandonment of large residential institutions and their replacement by small-scale services to enable people to live well in the community has probably been the most significant policy development in intellectual disability in the post-war period. This process of ‘deinstitutionalization’ is well-advanced in Scandinavia, the United States of America, Canada, the United Kingdom, and Australasia. In these countries, the policy debate about whether to provide institutions or community services is largely resolved.”<sup>111</sup>



Given this long history and current state of affairs, the following section of this report should by rights be a straightforward discussion of the merits of small group homes as compared to supported independent living.

Unfortunately, in Ontario we are seeing a resurgence of support for large-scale housing developments for people who have an intellectual disability. Therefore, this section will cover some old ground and assess the effectiveness and cost of (i) large congregate,

(ii) small group home, and (iii) supported independent living models. It will make the case that large congregate facilities have no place in our province, and that the **bulk of evidence shows that we can increasingly support greater independence at equal or lower cost compared to more restrictive options.**

## 2. Is there such thing as a good institution?

No history of social service provision in Canada would be complete without a chapter on the country's 'schools' and 'hospitals' for people labelled as having developmental disabilities. Thanks to the incredible bravery of the people forced into these institutions in telling their stories, we know that these places were appalling prisons rife with physical brutality, sexual abuse and assault, and emotional neglect.

There are some marginally positive stories to be found in the history of Ontario's provincial institutions for people who have an intellectual disability – but only during the years of their closure. As they wound down, their populations dwindled to a point where only a few dozen people with the highest physical, emotional and medical needs were left under the care of staff who generally knew them well and understood their needs.<sup>112</sup>

Given this somewhat positive recent history (and we must note that this era was not all positive), might it be possible to have large modern congregate facilities that are safe, responsive, connected to the broader community, respectful of human rights, and supportive of the needs of a population that is as poorly understood as people who have intellectual disabilities?

One way of answering this question is with reference to excerpts of the Canadian Armed Forces Report on Long Term Care in Ontario (note that the following may be disturbing for some readers):



“Canadian Armed Forces member[s] have witnessed aggressive behaviour which [armed forces] staff assessed as abusive/inappropriate. Incidents have been reported to management on numerous occasions... Examples include aggressiveness when changing incontinence product, not stopping or slowing when resident complained of pain, pulling residents, aggressive transfers impacting resident ability to participate in care as able (roll self in bed), degrading or inappropriate comments directed at residents, etc.”

“Forceful feeding observed by staff causing audible choking/aspiration, forceful hydration causing audible choking/aspiration...”

“Lack of knowledge evident regarding what qualifies as a restraint. Multiple scenarios of walking aids being removed, or mattresses set on floor as patients were unable to stand from that low position (to prevent them from wandering the facility).”

“At time of arrival many of the residents had been bed bound for several weeks; no evidence of residents being moved to wheelchair for parts of day, repositioned in bed, or washed properly.”<sup>113</sup>



The CEO of one of the five conglomerates documented in the report noted that he was “shocked and dismayed at some of the conditions” found in a building he continues to be responsible for as of January 2021.<sup>114</sup>

Thankfully, it has been many years since these types of institutions existed in the developmental service sector in Ontario. However, the worst-case scenarios described above show that too many have forgotten the lessons of the regional centres.

It must also be noted that a significant number of adults aged 19-65 who have developmental disabilities reside in long-term care facilities designed for seniors. A recent Ontario report found that more than 2,200 people who have developmental disabilities spent time in long-term care between 2010 and 2016.<sup>115</sup> While the care and support of this vulnerable population has improved exponentially, there continue to be gaps that expose people to abuse, neglect and poor health outcomes.

An institution is any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.

– People First of Canada and the Canadian Association of Community Living<sup>116</sup>



### 3. Congregation, choice and quality of life

Regardless of the presence or absence of neglect and abuse, large congregate facilities have consistently been found to offer the least choice and lowest quality of life for people who have an intellectual disability.

For example, a large study commissioned by the State Government of Victoria, Australia, examined the lives of 100 people who made the transition out of Kew Residential Services (KRS), the oldest and largest congregated facility in the country. It found that:

“Unequivocally the people with an intellectual disability who left KRS to live in small group homes experienced an increased quality of life. Significant positive changes occurred in: the homeliness of their place residence; the degree of choice they exercised; their community utilisation and person/social responsibility; their use of community facilities for leisure purposes and other activities; and the size of their social networks... Significant reductions were found in maladaptive behaviour, depersonalisation and block treatment.”<sup>117</sup>

Regardless of the presence or absence of neglect and abuse, large congregate facilities have consistently been found to offer the least choice and lowest quality of life for people who have an intellectual disability.

A recent international systematic review examined changes in quality of life over the course of people's move from large congregated facilities to group homes and supported independent living. The review found that "relocation to the community was associated with improved quality of life... [including in] physical well-being, community access, routines, self-determination, residential well-being, and general life improvements." The review found that this was true among people of all support need levels, though those with very high needs may not have benefitted "to the same degree as those with less complex needs."<sup>118</sup>

Similar outcomes were found in Ontario in the period directly following the closure of the province's last provincial institutions (a process known as the Facilities Initiative). A comprehensive series of studies concluded that "the reported outcomes of the Facilities Initiative for former facilities residents are

strikingly positive," with improvements in family and community engagement, privacy, self-determination and self-expression, as well as reductions in behaviours that tend to spur paid staff to administer physical and chemical restraints.<sup>119</sup>

In the United States, where larger congregated facilities continue to be common in some regions, people's choice and control are much more restricted in such settings. For example, a large study of nearly 2,500 adults who have a developmental disability found that those living in larger congregated settings exercised less choice in everyday decisions (e.g., when to wake, eat, bathe, etc.), and almost no choice in support decisions, when compared to those living in more independent housing options. (It must be noted that, compared to people who do not have disabilities, all people included in the study experienced relatively limited choice and control in their lives).<sup>120</sup>

## 4. The cost advantage of smaller residential settings

The issue of cost, and of what housing model – large facilities, group homes, or supported independent living – is least costly over the long run is the source of one of the developmental service sector's longest-running debates. While the comparison of costs across models is complex, there is substantial evidence showing that smaller and more independent settings can enable equivalent or better quality of life at lower cost.

It is widely recognized that large scale congregated care is expensive. In the US, state and federal governments spend an average of \$141,000 to support each person

living in Intermediate Care Facilities (i.e., larger congregated settings). In contrast, governments spend an average of \$44,000 per person living in smaller settings, including group homes, supported independent living and with family members.<sup>121</sup>

This cost comparison is imperfect, since larger congregated settings tend to house more people with higher needs and severe cognitive impairments (who require higher and more costly levels of support). While few available studies control for this factor, information from the US allows for detailed analyses.

For example, a 2008 study of more than 1,400 people across four US states found that, after controlling for level of support needs, community-based housing models – including living with family, in small group homes and in one’s own home – were “substantially less costly” to governments than larger congregated settings (it is noteworthy that US states tend to offer more generous levels of support to people who live with parents and siblings).<sup>122</sup> In a related report, the authors note that “although community-based services may be more expensive for a small number of individuals, overall, closing an institution yields cost savings.”<sup>123</sup>

Looking at more recent data from the US, it is notable that some states house significantly fewer people in large settings than others. For example:

- In 2015, the state of Arizona spent \$28 million to support a total of 131 people who have a developmental disability in Intermediate Care Facilities across the state (about \$210,000 per person). These are highly structured facilities which, in Arizona, exclusively serve people with very high physical and medical needs. In contrast, \$830 million was spent to support 28,000 people in smaller group, family and supported independent living situations (about \$29,000 per person).
- Altogether, Arizona spent an average of \$29,900 in 2015 for each person supported by developmental services, with almost no recourse to large congregate facilities.

- In the same year, the state of Texas spent \$1.1 billion to support 8,200 people in Intermediate Care Facilities (\$134,000 per person). Unlike in Arizona, these include larger facilities that house a broad range of people who have developmental disabilities. Additionally, Texas spent \$1.2 billion to support 35,000 people in smaller and more independent settings, with an emphasis on family homes, host families and supported independent living (\$36,000 per person).
- Altogether, Texas spent \$55,000 in 2015 for each person supported by developmental services - \$25,100 more than Arizona. If Texas supported even half of those housed in larger facilities to move into smaller and more independent settings, the state government could save up to \$400 million every year.

In 2019, Arizona was ranked 1<sup>st</sup> out of all US jurisdictions on its performance in supporting positive outcomes among people who have intellectual and developmental disabilities. Texas was ranked 49<sup>th</sup> – almost dead last.<sup>124</sup>

Arizona has clearly shown that it is possible to effectively do away with large, congregated facilities. The same is true of Vermont, New Mexico, Hawaii, Alabama, Alaska, and the District of Columbia (where zero people are housed in larger Intermediate Care Facilities) and in more than a dozen states where fewer than 1% of people who have developmental disabilities live in such settings.<sup>125</sup> Overall, the US example shows the decisive move away from large congregate facilities: just 3% of people who have a developmental disability and are supported by Medicaid live in residences housing more than 15 people, and these settings are concentrated in just a handful of states.<sup>126</sup>



## 5. Group homes, cost and quality of life

Countless organizations in Canada, the US and around the world have moved away from both large congregated and group home models of supported living. These agencies have divested of their homes and made the choice to offer mainly (or only) supports for independent living, with an eye to assisting people to live in the same manner as people who do not have an intellectual disability. Several studies have compared quality of life and cost of these two models.

A 2008 Australian study compared 58 people who lived in group homes or supported independent living, with research participants matched in terms of needs and challenging behaviours. The study found that per-person disability support expenditure “was significantly and substantially higher for group home participants” – largely due to higher staff costs. Non-monetary outcomes (including

safety, money management and quality of life) among people in supported independent living were consistently equal to or higher than among people living in group homes. In other words, those living more independently experienced equal or better outcomes with less paid support.<sup>128</sup>

A 2018 Australian study found that the quality of life of research participants in supported independent living was generally “comparable to people with similar characteristics living in group homes” (unfortunately, quality of life was characterized as mediocre for both groups). It is notable that, though participants’ need levels were similar across housing models, those living more independently made use of only four hours per week of paid support on average. Annual support costs were estimated at \$30,400 for those in supported independent living, compared to \$99,000 for those in group homes.<sup>129</sup>

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The group home seemed to us, at the time, a wonderful social innovation and we devoted our efforts, over many years to develop more and more of them. But, as we matured, we came to understand that we had not achieved anything close to the justice we sought... Most people we supported had few (in fact, often no) meaningful relationships, saw their staff come and go by the dozens, had no control over who they lived with, no say about who provided supports, and, with honest scrutiny, were not treated as individuals.

– **Christopher Liuzzo**, the Arc of Rensselaer County, New York<sup>127</sup>

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A similar study in the UK found that the average weekly cost of semi-independent living was one-third of that required for people living in fully staffed group homes. Each model showed some advantages: for example, people in group homes had better outcomes in money management and some elements of health care. People in supported independent living tended to be more independently involved in the community, to have more friends who did not have a disability, and exercised greater choice in their decisions. On other outcomes (e.g., body weight, exercise, loneliness, physical risk), neither model showed an advantage over the other.<sup>130</sup>

In a recent article, David Felce – lead author of the UK study referenced above, and a long-time researcher in the field – attempted to offer a

comprehensive statement on cost differences between large facilities, group homes, and supported independent living. He notes that increased staff costs do not predictably lead to gains in outcomes among people supported, and that it is very common for staff involvement to be unrelated to people's actual needs even in small congregated settings.<sup>131</sup>

There are many caveats to be considered when comparing group homes with supported independent living, and no housing option should be considered a panacea. Regardless of living situation, people who have intellectual and developmental disabilities are at high risk of experiencing chronic loneliness,<sup>132</sup> mental health problems,<sup>133</sup> violent victimization,<sup>134</sup> poor health outcomes, and problems accessing adequate and appropriate health care services.<sup>135</sup>

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While the research outlined here suggests that many people in congregated living facilities are unnecessarily over-supported, it is crucial that adequate, responsive and person-directed supports be available regardless of living situation.

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## 6. Separating housing from support

In Ontario, people who have an intellectual disability who are eligible for provincial supports generally get a package deal when they leave the waiting list: they are connected with a service provider that provides housing and the various supports a person needs. They are generally unable (unless they are paying out of pocket) to pick and choose multiple service providers for housing and supports.

A recent study led by researchers from Centennial College and Community Living Toronto discusses the separation of housing and support, noting that “significant positive change in the housing landscape could result from separating support from housing.”

The researchers make the case that separating developmental service supports from housing would “allow families and individuals with IDD to find their own housing solutions and to obtain the level of support they require, rather than forcing them to accept any available premade housing solution with built-in support simply because it is funded.”<sup>136</sup>

This change would increase the flexibility of housing, allowing people to change their living situation while keeping needed supports. It could also open the door to growth in funding for people who live with family members, thereby taking pressure off the overburdened and waitlisted developmental services sector, and addressing the unsustainable crisis of care among aging parents of people who have intellectual and developmental disabilities.

The Centennial/CLTO report draws attention to two important realities in Ontario:



60%

of Canadian adults who have a developmental disability live with family members (and are therefore eligible for only limited provincial government support),<sup>137</sup>



From 2009 to 2014, there was a

**50% increase**

in the number of people waiting for supported residential services in Ontario (increasing to more than 12,000 overall),<sup>138</sup> but only a 1% increase in people newly accessing such services.

The Ontario wait list shows the extent to which access to supportive housing is limited in the province. The 2016 report of the provincial ombudsman (*Nowhere to Turn*), as well as the 2014 report of the Auditor General, show that only people in situations of severe crisis – where family members can no longer provide care and support, and household breakdown is imminent or worse – tend to be offered funded spaces. Generally, these funded spaces consist of a room and staff support in a small congregated setting. There is generally a pool of several people in comparable states of crisis who are considered for a given space, and regional decision makers make the choice of which person is offered that space based on a number of characteristics.<sup>139</sup>

This situation is a far cry from the guidance provided by article 19 of the UN Convention on the Rights of Persons with Disabilities, which directs states to ensure that “persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.” It is also antithetical to what all Canadians want: the choice of a safe and stable place to live, with the amenities they need to live a healthy life.

Current policy on developmental services housing and support creates several problems:

- ❗ For people who have access to developmental services funding, all costs must be covered within the MCCSS funding envelope, and individuals and families are not able to add other sources of funding to expand their options;
- ❗ People often stay in negative housing situations because they are unable to do without the support connected to that housing;
- ❗ People rarely have the choice of who they live with, or the staff they engage with on a daily basis.

Developmental services funding is to a great extent roped off from the billions of dollars currently flowing from the federal government under the National Housing Strategy. The province’s developmental service waitlist, and the sector’s housing stock, are also separate and distinct from the larger community housing universe. The current situation severely limits the sector’s ability to serve people in need of housing, and chokes off innovation in the sector.

The separation of housing and support would:

- ✅ Allow developmental service agencies to more easily move people with lower support needs out of group homes and into more independent settings – thereby reducing support costs while maintaining funding for housing.
- ✅ Allow people greater choice and control over where and with whom they live, and by whom they are supported.
- ✅ Allow families to support adult children to move out of the family home while accessing needed supports that forestall crisis situations.
- ✅ Allow adults who so desire to continue to live with a family member, while accessing funding for needed developmental supports.
- ✅ Create greater equality for all people who have intellectual disabilities in Ontario – only some of whom receive funding support from the provincial government.

## 7. Moving forward on high quality, affordable, accessible housing and supports for people who have an intellectual disability

In many ways, changes to housing policy within developmental services is the keystone to bringing life to Ontario's long-held vision of true community inclusion and belonging. Individuals and families waiting for housing and support have been in crisis for too long, and we need innovative thinking, clear direction and real commitment on this issue if we are to make progress.

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The developmental service waiting list will not be significantly reduced through the creation of large-scale congregated facilities that cost millions to build, house relatively few people, and trail other models in supporting a high quality of life.

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While group homes will continue to have a role, this model is not enough. We must take advantage of existing housing stock – the same housing stock that is available to everyone – to expand our options, and to provide more opportunities for people supported by the sector to build natural supports and independence.

### We recommend the following:

- ✔ Prioritize investment in geographically distributed, semi-independent, affordable housing options (including rental and home ownership). Implement enabling factors including rent supplements, portable housing allowances, and municipal development requirements mandating a proportion of affordable units for people who have intellectual disabilities within new builds.
- ✔ Separate developmental housing and support funding envelopes to increase flexibility in the system, and to improve people's control over their living situation.
- ✔ Create a dedicated ten percent allocation of National Housing Strategy funding for the developmental services sector. While the current National Housing Strategy includes a target of 2,400 new affordable units for people who have a developmental disability,<sup>140</sup> a more ambitious target is required to meet existing need.
- ✔ Accelerate the sector's focus on distributed (as opposed to congregated) models of support and care in the community for people who have developmental disabilities. As housing options become increasingly distributed throughout the community, so must services and supports.



## D – From institutions, to group homes, to supported independent living >

- ✓ Ensure that all investments in new housing options include a focus on – and participation of – communities experiencing racialization and marginalization, including but not limited to Black, Indigenous and People of Colour.
- ✓ Ensure that all new housing developments meet or exceed the requirements of the Accessibility for Ontarians with Disabilities Act regarding universal design. Further – and as the Onley Report noted – a significant investment is required to retrofit existing buildings to be accessible to people who use mobility aids.<sup>141</sup>
- ✓ Invest in innovations in specialized (non-congregated) community housing options for people with high support needs, who exhibit destructive or self-injurious behaviour, people with mental health co-diagnoses, and older people who have an intellectual disability (with a focus on aging in place).
- ✓ Create a permanent provincial developmental services housing planning table (including but not limited to representatives from MAH, MCCSS, People First of Ontario, the Provincial Network on Developmental Services, the Canadian Housing and Renewal Association, and the Association of Municipalities Ontario) to help ensure a consistent and streamlined approach to one of the province's most challenging issues.<sup>142</sup>



Conclusions:

# Higher Expectations

This report has been heavily influenced by our experience of the pandemic. While people supported by the developmental service sector have been exponentially better protected from the virus than those in long-term care, that protection came with severe restrictions on their freedom of movement and choice. COVID-19 has shown the extent to which people who have intellectual disabilities are still not able to easily exercise the rights most Canadians take for granted.

The research that grounds this report clearly shows that Ontario has fallen behind other, more innovative jurisdictions in supporting people who have intellectual disabilities to live in a way that improves their self-determination, health, and quality of life. While there are pockets of innovation in the province, other jurisdictions are doing a much better job at building people's ability to make their own choices, determine their own futures, live more independently of organizations, and increase their quality of life.

Improvement in policy and practice starts with higher expectations. We must demand more of the provincial government, and of the developmental service sector it supports. We have the knowledge and resources to do better in our support of people who have intellectual disabilities, and a duty to keep pushing forward in the evolution of support to this population.

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Founded in 1953, Community Living Ontario is a non-profit, provincial confederation that advocates for people who have an intellectual disability to be fully included in all aspects of community life. For more information, go to [www.communitylivingontario.ca](http://www.communitylivingontario.ca).

We would like to express our sincere appreciation and thanks to everyone who reviewed and commented on this report in its draft form, as well as the advocates, researchers and authors on whose work it builds.

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