

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).⁸¹ 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.”⁸² 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.⁸³

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.”



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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, Amicus⁸⁴

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.

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.”⁸⁵

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 choice⁸⁶ – 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:⁸⁷



“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.⁸⁸ (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).⁸⁹

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 to try living in his own home... Since moving into his own place, he has had no need for rights restrictions or PRN medications.”⁹⁰



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.

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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.”⁹¹

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 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.



“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.”⁹²

– **Community Living Upper Ottawa Valley**

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.⁹³

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%.⁹⁴

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.⁹⁵

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.⁹⁶

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

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.⁹⁸

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 2004,⁹⁹ and no one is paid less than the minimum wage¹⁰⁰ – has consistently seen approximately 40% of residents with developmental disabilities in paid employment in the community,¹⁰¹ with an average of eight hours per week at about \$12 per hour.¹⁰²

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

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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.¹⁰⁴

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.¹⁰⁵

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:

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- 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.¹⁰⁶
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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.”¹⁰⁷ 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.”¹⁰⁸

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.¹⁰⁹

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.¹¹⁰

8. Multiple paths to change

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.

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-Kawarthas and Peel regions) and those slated for future implementation.