



Direct Funding for Developmental Services in Ontario: A Path Forward



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Preface: It's Time to Make Direct Funding a Reality in Ontario

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 often required to source and manage services.

The Government of Ontario's new strategy for developmental services, Journey to Belonging: Choice and Inclusion, includes a commitment to allow people to receive funding directly and manage their own supports. It is crucial that this change be implemented in a way that actually works for people and families.

This document contains five Policy Snapshots published by Community Living Ontario in the past year. Each snapshot offers direction and guidance on how we can finally make direct funding a reality in our province.

Community Living Ontario Policy Snapshot

The Benefits of Direct Funding for Developmental Services

Summary

Direct funding has been shown to have a number of benefits for people and families who choose it. This option tends to appeal to a minority of households – generally around 10-15% of families in jurisdictions where it is available. By building on lessons learned in other jurisdictions, the Government of Ontario’s plan for direct funding can spur improvements in quality of life for people who have intellectual and developmental disabilities.



In Ontario, there is a long history of advocacy for direct and individualized funding that would cover the full range of supports and services needed by people who have an intellectual or developmental disability.

- Direct funding is where people who need personal and health-related supports manage their own funds and pay for supports directly;
- Individualized funding is where people decide how a budget dedicated to their support needs is spent, but don’t necessarily manage funds directly.

Current examples of direct funding in Ontario include [Self-Managed Attendant Services](#) for adults with physical disabilities, [Family-Managed Home Care](#), and of course Passport and Special Services at Home (SSAH).

Community Living Ontario was pleased to see a focus on direct and individualized funding in Ontario’s reform plan for developmental services, [Journey to Belonging: Choice and Inclusion](#). Studies from Ontario, other provinces, and jurisdictions around the world are clear about two things related to direct funding: (1) it can be stressful and sometimes exhausting to be an employer and manage your own workers, and (2) most people find that the stress is worth it. Over the long run, having greater control over supports and

services [increases quality of life](#) among people with disabilities and their families.

Expanding direct funding beyond Passport and SSAH is likely to have a number of benefits for people who choose it. For example, it’s no secret that high [staff turnover](#) is a constant reality in developmental services. People and families are frequently assigned new workers, and need to regularly train new staff in how to assist them to meet their specific physical, social and emotional needs. The ability to create meaningful and flexible long-term relationships with paid staff is a unique feature of direct funding. For workers, a direct relationship with a family is fundamentally different from a relationship to an employer.

Direct funding can be especially valuable for people and families for whom English is not their first language, as it can increase their ability to hire from within their own linguistic and cultural communities. For people with limited verbal capacity and who have grown up surrounded by the sounds of their first language, having a fluent worker can have measurable emotional benefits (with a bonus for workers who can artfully prepare culturally-appropriate foods). And from a practical perspective, the ability to fluently communicate care instructions can lead to less physical discomfort and pain during



personal care routines.

A small [recent study](#) from the United Kingdom underlines these advantages among people with developmental disabilities who have high support needs. Over the course of interviews with family carers managing direct funding, researchers found that:

- Switching to direct funding has increased families' choice and control over services and supports. For example, workers can be assessed and matched on mutual interests, aspirations and personal outlook, increasing the likelihood of a deeper relationship between supporting and supported parties. Families can also hire from their own social and family circles.
- Families report greater consistency and less turnover, as well as access to workers' own social networks when additional or substitute assistance is required.
- Families report significantly fewer restraints on care times and locations. Thus, support workers can more easily transition from home to community-based programs (rather than having separate workers for different programs), support people in health care facilities, while on holiday, etc.

Direct funding is not the definitive solution to all of our problems, and it comes with its own downsides. For example, in many jurisdictions families have reported that direct funding budgets are not adequate to need, and that they are unable to purchase needed supports because they are not available in their region.

Direct funding also tends to appeal to a minority of people with disabilities and their families. For example, despite positive outcomes among participants, only about 1,000 people utilize Ontario's Self-Managed Attendant Services program. Uptake is likewise relatively low in the four western provinces that make direct funding available to people who have a developmental disability: the option has been chosen by about six percent of people supported in [British Columbia](#), 10% in [Alberta](#), and

approximately 20% in Manitoba.

The fact remains that direct funding is highly valued by those who choose it. Families tell us that they don't understand why direct funding isn't already an option in Ontario. It is an approach that has been implemented with success in jurisdictions around the world, and that has been successfully piloted with Passport and SSAH. It is a proven and logical approach that will increase quality of life among those who choose it, and that can take pressure off of our overburdened developmental service system. Agencies will always have a central place in supporting people with developmental disabilities, but it is time to increase flexibility and innovation in the system with new options.

(First published in August 2021)

Community Living Ontario Policy Snapshot

Lessons from Direct Funding in Alberta and British Columbia

Summary

Alberta and British Columbia have long-standing and well-developed direct funding programs for people who have an intellectual or developmental disability. As Ontario develops its own stream of direct funding, it is important to learn from the experience of other jurisdictions.



The Western Canadian Approach to Direct Funding

Every province to the west of Ontario has made direct funding available for people who have an intellectual disability. BC and Alberta in particular have a long and well-developed history of direct funding, and both make it possible for people to receive support via either (a) block-funded agency services or (b) direct funding. Canada's westernmost provinces offer valuable insights, since their programs are quite similar to what is outlined in Ontario's [new developmental service strategy](#), which states:

We want to give people greater choice and flexibility to better meet their needs. This means introducing different ways people can get supports. People could continue receiving supports from service providers or choose to manage their funding directly. It could also mean a combination of both.

Individualized Funding in British Columbia

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 through the program must have a representation agreement that identifies an agent with [legal](#)

[authority](#) to act on the person's behalf (it is worth noting that there are major differences between BC's representation agreements and Ontario's system of substitute decision-making).

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](#). It is possible for people – with support from family members or other representatives as needed – to manage their own finances, develop a microboard, or work with a Host Agency that manages funds [in consultation with them](#).

As of 2019, [1,152 people](#) accessed direct funding for support services (not including respite) in the province, accounting for 6% of people receiving support through CLBC. The province also offers direct funding to families for respite services.

BC is well known for its use of microboards, i.e., 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 person to create a life plan, advocate for what they need, and [manage funds and services](#). Microboards are [involved in](#) about 20% of individualized funding relationships with CLBC; direct-

funded respite accounts for 65% of cases, and direct (non-microboard) and host agency funding make up the remaining 15%.

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.”

Family Managed Services in Alberta

In Alberta, the [Family Managed Services](#) (FMS) program was launched in 2006, and allows for a person, their family or a person close to them to manage the delivery of services by hiring staff directly or by obtaining supports through an approved service provider. The program built on decades of below-the-radar direct funding to families of people who have a developmental disability [beginning in the 1970s](#).

Family Managed Services (FMS) funds are most often administered by family members; however, it is also possible for non-family members of a person’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. Despite this administrative burden, 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.

Alberta has developed a substantial infrastructure to support direct funding. The province provides a broad set of resources that balance 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.

It is notable that FMS is available to people who have ‘complex service needs,’ defined as people “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.

Our Recommendations for Direct Funding in Ontario

In our recent document, [Building a Full Life & A Home of One’s Own in the Community](#), Community Living Ontario makes a number of recommendations for direct funding in Ontario, inspired by programs in BC, Alberta, the United Kingdom, and the United States. Our recommendations include the following:

1. 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.
2. Direct funding agreements will include all items available via block-funded agency agreements and the existing Passport program. The cost of services and supports set out in the plans of people supported must be equal to or lower than those provided via block-funded agency agreements.
3. 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:

- A detailed outline of services and supports that will be purchased from agencies and/or individuals (including planning supports),
 - 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
 - The role of in-kind and unpaid supports from personal support networks (often referred to as 'natural supports').
4. It is recommended that more intensive plans (e.g., requiring more than \$50,000 in program funds) require the engagement of facilitation and management support.
 5. Advance funding will be made available on a quarterly basis, with a requirement for regular financial reporting to the funding/oversight agency.
 6. 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.

Community Living Ontario is pleased that the Ministry of Children, Community and Social Services has embarked on the development of a direct funding program in our province. This is a long-anticipated development among people and families, and it is crucial that we learn from other jurisdictions and get it right the first time.

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Community Living Ontario Policy Snapshot

Learning from New York State's *Self-Directed Services* Program

Summary

New York State's *Self-Directed Services* is a program that provides funding directly to people and families, so they can manage and control their own disability-related supports. The program provides a helpful case study and offers several lessons for Ontario as we plan to make direct funding a reality in the province.



Building on Lessons Learned

Ontario's new strategy for developmental services, *Journey to Belonging: Choice and Inclusion* (J2B), includes a plan to implement direct funding – where eligible people and families receive funds to source and manage their own supports. J2B states:

We want to give people greater choice and flexibility to better meet their needs. This means introducing different ways people can get supports. People could continue receiving supports from service providers or choose to manage their funding directly. It could also mean a combination of both.

A total of forty-two US states offer direct funding as a choice for people supported by developmental services. This includes New York, where [direct funding](#) is managed through the Office for People with Developmental Disabilities (OPWDD). This option provides people with direct funding via [Personal Resource Accounts](#) that are based on a person's assessed needs. People can choose to self-direct some or all of their supports and services.

There are notable similarities between the developmental service systems in Ontario

and New York. Both share a dark history of institutionalization, and a more recent history of increasing individualization and person-centred supports, led by self-advocates and parent groups. Both jurisdictions have a varied and complex range of service provision, advocacy, and facilitation groups; both have a system of regional offices that are responsible for determining eligibility for funding, conducting system intake, and helping to coordinate and oversee programs, supports, and services.

Lowering Barriers to Direct Funding

New York State has made some interesting strides in supporting independence and respecting decision-making rights among people who have an intellectual disability. For example, like many states, New York has implemented a *representative payee* system, an alternative to guardianship whereby organizations can accept and disburse funds on behalf of – and, importantly, following the wishes of – people considered incapable of managing direct funding on their own. The state has also made strides in supporting equal access to direct funding, particularly for people who don't have large circles of support. For example, New York has

developed the following key system elements:

- **Care Coordination Organizations:** Similar in scope to independent facilitators in Ontario, these organizations oversee and employ Care Managers (see below), and partner with service providers to plan and coordinate supports for people who wish to direct their own services.
- **Care Managers** oversee and help to coordinate access to all services; support people and families through the self-direction process; and work collaboratively with Support Brokers and Financial Intermediaries (see below).
- **Support Brokers** are personally hired by people with developmental disabilities (often with assistance from their circle of support) to help create and implement life plans; manage budgets and work with Fiscal Intermediaries to bill for services; hire, train and supervise support staff; negotiate rates for supports; and help expand circles of friends and other allies in the community.
- **Fiscal Intermediaries** are non-profit organizations authorized to assist people with the management and payment of their self-directed budgets.
- **Paid Neighbours** are people who live relatively close to a person who is self-directing their services, and receive a stipend to be 'on-call' for emergencies, and as back-up when scheduled services and supports fall through. The stipend can be provided to a maximum of \$800 per month, which can cover a significant portion of a supporter's rent (a person can also have multiple paid neighbours).
- **Live-in Caregivers** can be hired to live in a home owned or rented by the person supported, and are meant to

offer [companionship and protection](#) on an ongoing basis. Live-in caregivers receive free room and board, and can also receive wages for services provided.

As is generally the case with self-directed programs, all of these roles add complexity and require their own sets of paperwork. Despite this fact, the [number of people](#) utilizing self-direction grew from 5,200 in 2016 to 18,300 in 2020, and accounted for 15% of all people accessing Medicaid funding via the OPWDD.

The move to self-direction in New York has clearly benefited from partnerships between the OPWDD and representative groups, including the Statewide Advocacy Network of NY (SWAN), the New York Self-Determination Coalition (NYSELFD), and Self-Direction NYC. There are a number of up-to-date resources and guides available online (for example, see [In the Driver's Seat, New York Alliance for Inclusion and Innovation](#), and [this guide](#) on self-direction), and the OPWDD has been open in publishing useful [statistics](#) on use of the program.

The New York Experience offers some key takeaways for Ontario, particularly when it comes to increasing the attractiveness and accessibility of direct funding for people who do not have strong circles of unpaid support. It suggests that, for direct funding to be taken up by as many people as could benefit from it, we will need to ensure that appropriate and effective community-based supports are available and accessible.

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Community Living Ontario Policy Snapshot

Lessons from Australia's National Disability Insurance Scheme (NDIS)

Summary

The Ontario government is currently planning a reform of the province's approach to developmental services (DS). In this context, it is important to understand the experience of other jurisdictions that have reformed their DS systems.

Australia's National Disability Insurance Scheme (NDIS) is often referenced as a leading example of disability service reform, and there is much to learn from the country's experience. However, the NDIS has been plagued by a number of issues – especially for people who have an intellectual disability – and it is crucial that we learn from Australia's mistakes.



In Australia, much has been made of the [negative aspects](#) of the National Disability Insurance Scheme (NDIS) launched in 2016. 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 often overburdened by policy restrictions that suppressed innovation;
- Focused on addressing crisis situations, rather than early intervention;
- Triage and rationed so that only a proportion of people in need were supported;
- Complex and confusing for end users, with little personalization or flexibility.

These [criticisms](#) are remarkably similar to those made by the provincial Ombudsman in

his 2016 [report](#) on Ontario's developmental service system.

Positive aspects of the NDIS

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.”

The new program was bolstered by increased funding for disability-related services, and this seems to have contributed to better access to needed supports for many participants. It is notable that people who are covered by the NDIS tend to [report](#) greater satisfaction than those who are not covered. At the same time, the implementation of the NDIS



was a momentous transformation, and any transition of this magnitude risks substantial drawbacks.

Ongoing problems with the NDIS

The downsides of the NDIS provide an important reminder that disability service system users require ongoing assistance with understanding, navigating and advocating within such a system. People with Disability Australia 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.”

This criticism was also made in an arm’s length [evaluation](#) of the NDIS, which noted 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.”

Similarly, 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.”

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

The implementation of the NDIS has also been challenging for service providers.

According to a recent [report](#) published by National Disability Services, between 20% and 30% of organizations participating in the NDIS reported a deficit/loss in each year since the new program was put in place. There are unresolved concerns about the pricing of services and the ability of providers to offer quality services with current funding levels.

As a national effort to make services and supports available to every person who has a disability in Australia, the NDIS is an important case study. It is an admirable attempt to eliminate wait lists and increase personalization and control over disability supports. However, the program has presented serious difficulties for people who have an intellectual disability, problems with system navigation, and existential challenges for service providers. The next few years will be critical in understanding if and how Australia’s efforts have led to increased quality of life for people who have a disability, including people who have an intellectual disability. In the meantime, we must be cautious of following Australia’s lead too closely.

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Community Living Ontario Policy Snapshot

Community Living Ontario's Recommendations for Direct Funding

In its recently-released developmental services reform plan, *Journey to Belonging: Choice and Inclusion*, the Ministry of Children, Community and Social Services highlighted individualized and direct funding as a major focus of its planned reforms:

"We want to give people greater choice and flexibility to better meet their needs. This means introducing different ways people can get supports. People could continue receiving supports from service providers or choose to manage their funding directly. It could also mean a combination of both."

Many stakeholders in Ontario have advocated for direct funding – where people manage and pay for their own supports rather than choosing options offered by a service agency – for several decades, and Community Living Ontario supports this policy direction.

The MCCSS plan speaks to the potential influence of direct funding on service quality in the province:

"Moving towards a funding approach that gives people greater choice and control over their supports will play an important role in promoting service quality. Individualized funding can encourage service providers to innovate and provide high quality services that deliver the best possible outcomes for people."

The provincial government's plan seems to envision a system where people can control

their funding rather than being matched with a limited number of service agencies, and where agencies will improve their services in order to compete for market share:

"Our plan will... help people better understand and choose quality services through a transparent quality framework [and] promote healthy competition among providers and reward innovators."

CLO supports the growth of direct funding because it has been shown to increase flexibility, control, and quality of life for people and families who choose this option. It also tends to decrease per-person costs of government-funded supports, since people using direct funding are more likely to build natural supports in the community and need less paid support. However, we believe that more work is required to understand how the change may affect overall service quality.

In Canadian provinces where direct funding is already available, uptake tends to be relatively low. The direct funding option has been chosen by about six percent of people supported in [British Columbia](#), 10% in [Alberta](#), and up to 20% in Manitoba. In the [United States](#), 12% of people with developmental disabilities supported across forty-two states access some level of direct funding. In the United Kingdom, where there has been a national push toward personalized budgets and direct funding, this rises to a quarter of all people with disabilities, seniors and people with mental health issues. Growth in the [UK](#)

has been spurred by the wide availability of services to assist people and families to take on the responsibilities involved in hiring their own support staff.

Research from direct funding pilots in [Saskatchewan](#) has shown that, while managing direct funding can be challenging, people and families consistently report that it is worth it. However, significant growth in direct funding will only occur if there are clear and consistent resources to support people and families in taking on the increased responsibilities of this approach.

Our recent report, [Building a Full Life + A Home of One's Own in the Community](#), puts forward a number of recommendations for direct funding in Ontario, including 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.
- Building on lessons learned from the Passport program, implement a direct funding infrastructure wherein:

- o Funded services and supports will include all items available via block-funded agency agreements and the existing Passport program. The cost of services and supports set out in individualized plans must be equal to or lower than those provided via block-funded agency agreements.

- o Plan managers (e.g., 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 recommended that more intensive plans (e.g., above \$50,000) require the engagement of facilitation and management support.

- o Advance funding will be made available on a quarterly basis, with a requirement for regular financial reporting to the funding/oversight agency.

- o Safeguarding people, fiscal responsibility and reporting will be key areas of focus, particularly in the planning and approval stages, with annual meetings required between plan managers, people accessing supports, and funding/oversight agency representatives.

- Following the precedent set by the Passport program, allow people who have developmental disabilities to choose supporters to assist them with making service decisions and managing funds, without recourse to guardianship.

- 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.

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About Community Living Ontario

Community Living Ontario is a non-profit provincial association that has been advocating for people who have an intellectual disability and their families for over 65 years. We proudly work alongside over 100 local agencies and advocate on behalf of more than 80,000 people across Ontario.

For more information about Community Living Ontario's research and recommendations on direct funding, please contact Shawn Pegg, Director of Policy and Strategic Initiatives at shawn@communitylivingontario.ca.

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