




A Proposal for Individualized and Direct Funding of Developmental Services in Ontario

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If you have any thoughts/comments, please reach out to:

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Introduction

Community Living Toronto, Karis Disability Services, Microboards Ontario, and Community Living Ontario have come together to create a shared vision on the topic of expanding individualized and direct funding for developmental services in Ontario. This document contains the group's priorities, testimonials of people and families, and recommendations for the provincial government. It builds on the experiences of people, families, and agencies that are already utilizing individualized and direct funding in the province.

Individualized Funding: When people decide how a budget dedicated to their personal, community participation and residential support needs is spent, but don't necessarily manage funds directly.

Direct Funding: A form of individualized funding where people who need personal, community participation and residential supports manage and administer their own funds and pay for supports directly, often with assistance from family and/or other supporters. Current Ontario examples include Passport, the Ontario Autism Program, Family-Managed Home Care, and Self-Managed Attendant Services.



Proposal:

We are excited by the potential that *Journey to Belonging: Choice and Inclusion* has to make developmental services funding more flexible, portable, and tailored to people's needs. For example, the strategy talks about "introducing different ways people can get supports," and the idea that "people could continue receiving supports from service providers or choose to manage their funding directly" (or a combination of the two). We strongly support and encourage the government to take this direction to enable individual choice, control, and autonomy.

For many years, the Ministry of Children, Community and Social Services (MCCSS) has been open to implementing innovative and forward-thinking models of support and care in developmental services. The Developmental Services Housing Task Force is an example of this, as is the current focus on assisting people with lower support needs and aging parents to achieve greater independence before reaching a crisis point in their lives. Additionally, the research the Ministry has performed on a number of agencies' innovative approaches to vacancy management has been helpful. These and other initiatives show that *Journey to Belonging* can build on current and recent practice.

We envision a system of individualized and direct funding that builds on current strengths while improving access to needed services and supports. Our vision is informed by more than 70 years of pioneering work by self-advocates, parents, and sector leaders in Ontario and across Canada and North America.

We are putting forward several principles to guide the creation of a system of individualized and direct funding in Ontario. We envision a system where people control how their developmental service funding is used, and where people have the option of choosing to receive and manage their funding directly. All options support accountability and transparency. This system would be defined by:

1. Resources and adequacy:

Support budgets must be adequate to need, and must support decent wages for workers. Funding levels must change based on changing circumstances (as identified via a responsive re-assessment process) and increases in the cost of living.

Currently, re-assessment is triggered by changing needs. It is crucial that changing circumstances also factor into re-assessments, as changes in people's housing, personal support networks, etc., can significantly impact their lives.

Consideration must also be given to front-loading funding so that people, families and agencies are not in a deficit; allocating funding on a quarterly or semi-annual basis will ensure sufficient accountability and minimize financial hardship.

It is also crucial that housing costs, as well as the cost of professional services, are eligible to be covered under direct funding agreements. Currently, the Social Inclusion Act and its regulations exclude these categories from eligibility for direct funding agreements. At current levels, the Ontario Disability Support Program is woefully insufficient to cover the true cost of housing. This shortcoming will drastically limit the applicability of direct funding.

2. Portability:

Ensure that developmental service funds are connected to people rather than system vacancies. Allow people to self-manage their funding (with support where needed, including the support of trusted family and friends, a Microboard, etc.), move funding from one service agency to another, or from one region to another. Give people the option to work with multiple service providers, for example choosing separate providers for planning, support, and housing.

The Resources and Capabilities Committee of Community Living Ontario has proposed a three-level model of individualized funding:

Person - led (i.e., direct funding):

- The person chooses to receive funding directly and use it to purchase supports, services, and needed items.

Supported individualized funding:

- The person chooses to have funding managed by an agency with the person directing how it is spent.

Agency - led funding:

- The person chooses to have funding paid to an agency that is responsible for providing a full range of services and supports.



3. Broad eligibility:

Offer an individualized and 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. This includes people with significant medical and/or behavioural needs, people who use substances, people who have experienced homelessness, and more generally people who have struggled to find effective support from traditionally-funded agency care.

4. Planning and facilitation supports:

While direct funding has been shown to increase well-being and life satisfaction (in addition to being cost-effective), it is labour-intensive. Because of this, a minority of people and families tend to choose the option. To increase uptake of direct funding, MCCSS must support the creation of relevant resources, guides, and peer networks. It must also recognize options such as Microboards, which reduce pressure and work for families, provide fiduciary accountability, and have built-in succession planning.

To reduce system complexity and allow people and families to take advantage of available resources, MCCSS must also fund navigation, planning, and facilitation supports and training. These services provide critical guidance and support, and help ensure that person-directed approaches are upheld.

5. Inclusive communities:

We are supportive of policy and program limits on what type of residential settings, as well as programs and services, are eligible to be created with MCCSS funding. *Journey to Belonging* must ensure that we continue the province's evolution away from institutionalization and toward individualization and the achievement of typical, inclusive lives in community.


6. Choice, control and self-determination:

When people who have an intellectual disability are offered increased opportunities to have choice and control in their lives (a central promise of *Journey to Belonging*), this often comes with a focus on mental capability and a push toward capacity assessment. With increased individualization and choice, it is crucial that people not be pushed into capacity assessments, which frequently result in a loss of rights. We also feel strongly that the province must move away from guardianship as a default, and toward a supported decision-making framework that enables choice and empowerment.

When implementing individualized and direct funding, MCCSS must also be attentive to the benefits increased control will have for racialized and other marginalized communities. This includes the ability to hire staff from one's own cultural community, and to direct funding to organizations that understand cultural safety, have a diverse staff complement, and have demonstrated the capacity to effectively respond to a diverse range of needs.

7. System sustainability and transition supports:

Journey to Belonging proposes a completely new funding model for the sector. The transition to the new model is likely to result in significant upheaval for organizations, risks to the safety of people supported, and potentially the shuttering of some service agencies. It will be necessary to make funds available for workforce planning/development/transition, for contingencies in situations that put people's safety at risk, and for a permanent base funding envelope for key agency activities that are unfunded within the new model.



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8. Accountability:

We recognize that administering direct funding is complex, that MCCSS may require direct funding to be administered via Transfer Payment Agencies, and that the Ministry might not allow for funding to flow directly to people and families. If this is the case, direct funding should be flowed through not-for-profit organizations, including Microboards, that have the experience, capacity, and commitment to the person to assist them in managing funding. As well, they should be able to oversee safety and protection of the person, including a modified Quality Assurance Measures strategy applicable to those who manage their own funds.



Moving Forward on Individualized and Direct Funding:

It is our hope that MCCSS will continue to partner with people, families, and developmental service organizations to create a system that builds on the successes of the past while addressing current system drawbacks and gaps. We are recommending several actions as part of such a partnership:

- Perform in-depth interviews with people, family members, Microboards and other supporters in Ontario that have successfully managed individualized and direct funding for developmental services.
- Undertake studies of individualized funding initiatives that are currently being managed by organizations in Ontario, or that have been proposed, piloted or fully implemented in the province (including the Housing Task Force and Innovative Residential Model Initiative).
- Pilot innovative options for individualized and direct funding now so that MCCSS is confident that its decisions result in success for all parties, and enable more families to receive support in planning for the future.
- Begin to track people and families' preferences by asking people what they want specifically and how they want to be supported for individualized and direct funding in the DSO application process. Data should be collected in DSCIS so that MCCSS and other stakeholders can assess and respond to the demand for these approaches.

People and families, with the support of agencies, have been calling for the broad implementation of individualized and direct funding for decades, and we are confident that Ontario can create a system that improves outcomes for people while effectively managing risk and ensuring accountability. It is crucial that we understand current examples of individualization and use this experience to assist in creating a system that will work within the unique history of our province.

Appendix A: Testimonials

(Note: some names, i.e., those in quotation marks, have been changed to protect privacy)

‘Christopher’

‘Christopher’ is a young man in his 20s who likes nothing better than walking in the country with his dogs, with people he is familiar with and trusts. He currently lives at home with his mom in a quiet rural area.

Christopher has been diagnosed with an intellectual disability and mental illness with psychosis, and he regularly experiences health-related complications. He has also experienced substantial trauma in his life, including physical, emotional, and sexual abuse, and suffers from Post Traumatic Stress Disorder as a result. Despite having some outside help, his mom had to quit her job because of the intensity of support he requires.

MCCSS has worked with a developmental service agency to create a plan to support Christopher and another young man together in a house of their own. However, his mom, his physician, and a ministry-funded clinical service provider all share the view that he will be destabilized by this kind of change. They have created a proposal that would see Christopher supported in a ‘granny suite’ on the family property, with capital costs covered by the family. Unfortunately, ministry policy largely continues to require adults to leave their family home in order to access significant developmental service funding (though exceptions to this rule are common). As a result, the family has been in a painful limbo for several years.

If Christopher and his family were able to access direct funding and take a larger role in managing his support, it would provide him with much-needed stability. It would also reduce costs for the province and open up an agency space for a person on the waiting list for services.

‘Elliot’

‘Elliot’ lives on his own and is able to manage his life with some practical supports from a developmental service agency. While his finances are pretty tight, he is able to make things work with income from ODSP, Passport, a part-time job, and funding from the LIGHTS program.

Elliot has very specific routines and social expectations that make living with other people challenging. If his routines are not kept, he experiences extreme anxiety, becomes unable to do simple tasks, and may become aggressive toward others. Having his own place is a stretch financially, but it’s worth it for the emotional equilibrium it provides.

The charitable LIGHTS program, which offers up to \$25,000 per year in direct funding over five years, has enabled Elliot to afford an apartment on his own, and to access emotional and behavioural supports. Without ongoing individualized funding beyond the 5 years, he will be at risk of losing his job, his apartment, and his supports. If this were to happen, he would likely be forced to return to group living options that would negatively impact his mental health, dismantle the life he has worked so hard to build, and increase costs for the province.



‘Susan’

Kelly and Earl adopted ‘Susan,’ who has a rare combination of complex physical and developmental disabilities, as an infant. They exhaustively searched the world, largely without success, to find experts in this complex combination of disabilities to guide them in parenting. They have had to creatively invent new strategies and advocate intensively for Susan’s rights and needs.

Individualized funding has played a major role in their success. Before they were able to obtain individualized funding, supporting Susan at home was exacting an extraordinary personal, physical, emotional and financial toll on them. As they aged, health challenges (including a major health crisis) made things even more difficult.

Since gaining access to individualized funding, Kelly and Earl have been able to support Susan in their loving and supportive family home with much less stress, where she has thrived to an unforeseen degree. It is their goal to support Susan at home for as long as they are able. They are extraordinarily grateful to be able to access individualized funding, and don’t know how most parents could cope with these challenges without it.


Natalie

Natalie is a young woman who has a developmental disability. Her family led the creation of a Microboard, which they named Spread Our Wings with Natalie (SOWWN). The Microboard then submitted a Supportive Individual Living Plan to MCCSS. The plan shows that the ministry would save money by flowing funds to the Microboard, which would be responsible for managing services to support Natalie in her own home. While they have not been successful in obtaining direct funding, Natalie’s mom, Carole, says that “Having a Microboard has been the vital key to providing our daughter with the life she deserves, wishes for and wants. It’s like a warm fuzzy blanket on a blizzard night.”

Beth

‘Beth’s Extra Special Team’ (BEST) is a federally-incorporated Microboard that helps Beth manage her Passport funding and decide what supports and services are most valuable to her needs and desires. While Beth’s mom is the official Person Managing Funds for Passport, the Microboard has been set up to assist her over the long term, including when her mom becomes unable to support her. It is their hope that when Beth is approved for additional funding via Developmental Services Ontario, the Microboard will become the agent for that funding to flow through.

Beth and her mom feel strongly that control of funding should rest with Beth herself, assisted by those who have officially committed themselves as directors of the Microboard. They are her advisors and supporters, now and in the future. The family’s experience is that organizations are unable to gain sufficient knowledge of Beth’s needs and desires, and face too many barriers to developing an ongoing personal relationship of support in decision-making, which means an agency cannot manage Beth’s funds effectively.



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Appendix B: Individualized and Direct Funding in Other Jurisdictions

Individualized and direct funding programs have been in place in jurisdictions around the world for several decades. A recent international review of 73 studies of individualized funding found that the approach contributes to higher quality of life, user satisfaction, and safety. Direct funding recipients report higher self-image and self-belief, as well as improved community integration. Overall, people prefer direct funding over traditional supports, even when they struggle with administration and program bureaucracy.

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. People can also access a combination of direct payments and state-funded agency supports. Multiple lines of research have found that:

“... 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.”



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. 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.

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.”

In the **United States**, forty-two states make direct funding (often referred to as ‘self-directed supports’) widely available to people who have an intellectual disability. 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. Across states, 12% of all supported individuals have chosen the direct funding option.

In **Australia**, the implementation of the National Disability Insurance Scheme introduced direct funding for disability-related services on a massive scale. While the NDIS has been controversial, satisfaction among people with disabilities has been strong. For example, 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 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 who are not covered. Families can also choose to flow their funding through a Microboard, and can use their funding to purchase support for its development from Microboards Australia.

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. 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 – in many cases assisted by family members or other representatives – to manage their own finances, develop a Microboard to manage finances, or work with a Host Agency that manages funds in consultation with them.

As of 2019, 1,152 people accessed some form of direct funding in the province, accounting for 6% of people receiving support through CLBC. There are approximately 1,200 microboards in operation in the province.

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.” Approximately 10% of people (about 1,200 individuals) supported by the Alberta Persons with Developmental Disabilities program access FMS.

In **Saskatchewan**, self-directed funding has been available to people who have an intellectual disability since 2017. People can choose to receive direct funding for residential and day supports including assistance with personal care, employment, and volunteering. People receive the same amount of funds that they would be able to access if they opted for a traditional agency model of funding.

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. 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 this program.



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