

**Direct Funding and Accountability:
What is of Prime Importance?**

*Report from the Ad Hoc Working Group of the
Individualized Funding Coalition for Ontario*

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Many thanks, to the individuals who have inspired and motivated their family members and friends (mothers, fathers, sisters, brothers and others) along their journey. Many thanks, to those family members who gave freely of their personal time to be part of the 'ad hoc working group'. Thank you for openly and willingly sharing your vast knowledge and experience. Your collective contribution has made a difference in the body of knowledge that the Individualized Funding Coalition for Ontario has have been able to document.

Individualized Funding Coalition for Ontario

*Ad Hoc Working Group of the Individualized Funding Coalition for Ontario
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Preamble:

The new developmental services legislation, the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* clearly lays out direct funding as a key mechanism for individuals who have a developmental disability to secure services and supports once they reach adulthood. It is imperative, that with this change in direction, individuals who have a developmental disability, their family/friends have input into how direct funding is conceived and implemented at a practical level.

Over a year ago, individuals who have a developmental disability and their families from across the province who have had experience administering some form of individualized funding came together to create an Ad Hoc Working Group to explore themes and issues surrounding the new Act. The latest gathering in September 2010 looked specifically at each family's experience with direct funding and focused on clarifying key principles for ensuring family accountability. The group spent the day reflecting on the following question:

Over time, what kinds of policies, practices and structures will make it easier for more people with disabilities and their families to act as agents in customizing the assistance they require?

The group discussed how important it was at this time for individuals and families to clearly articulate what their responsibility is in regard to moving direct funding forward and what is the government's responsibility. The consensus was that individuals and families must focus on building capacity and vision among and within families so that they can ensure good outcomes while the government's responsibility is ensuring coherent policy and practice.

Individuals who have a developmental disability, their family/friends must be clear about what they hope to achieve through choosing direct funding as an option. They need to be able to share their vision of a better future and how they intend to get there using direct funding.

The most important direct funding outcome identified by the group was having control and autonomy over day to day life and decisions. This desire for control and choice was aimed at creating a productive and interconnected life where the individual is assisted to be a valued member of their community. It was also directed equally to reducing the person's vulnerability.

Shared Beliefs and Principles:

We firmly believe in respecting the inherent dignity of each person; regardless of age, ability, impairment, history of past acts, and social status. This belief implies, among other things, that we recognize our shared humanity with other people, particularly socially devalued people. The inherent dignity of all people calls us to desire and to work toward the good of others. We realize that our good is wedded to the good of others, and that what hurts others also hurts us.

We believe in the importance for both those who serve and those who are served of assuming personal moral responsibility for their actions. This implies, among other things, trying to do the right thing, ideally regardless of the potential cost to oneself. We are responsible for the impacts of our actions. Therefore, we should resist the pressures and temptations to hand our responsibility over to a government body, an agency, or those above us on an organizational chart. We believe that it is also important to invite others to take responsibility for their own actions. We should all strive to avoid human service approaches such as restraint which are rooted in the use of control *over* other people, particularly adults, in favour of more equitable approaches which uphold personal dignity, morality and responsibility.

We believe in trying to provide services and supports at the lowest level of formality which is effective. This belief implies, among other things, that those with the closest knowledge of a problem should be directly involved in problem-solving. It is essential to build personal connections with others which are not dependent on formal organizations. We should use as much as possible typical resources (i.e., family, friends, neighbours, work, school, faith communities, etc.) and typical approaches (i.e., effective teaching strategies, positive role modeling, high expectations, positive physical and social environments, etc.) when serving others. We should strive to reduce unnecessary bureaucracy, formalization and complexity within our services, programs and agencies as much as possible.

(Extracted from CAR report, 2006)

What is of Prime Importance to Individuals and their Family/Friends?

Through the work of the group, there was consensus reached about what was of prime importance to individuals who have a developmental disability and their family/friends in relation to Direct Funding.

Direct Funding must be:

- A viable choice
- Adequately and equitably funded
- Sustainable over time
- A mechanism that promotes effective partnerships between individuals, their family and friends, independent facilitators and supportive agencies
- Easy to understand and interpret
- Simple to administer
- Written and communicated in plain language
- Able to include an agreement that recognizes the legal capacity of the individual receiving the funds and provides accommodation to the individual for 'supported decision making'
- Directed at assisting the individual to build a more meaningful life in the community with valued social roles and opportunities for contributing
- A vehicle that recognizes the natural authority of the family

1) A viable choice:

For direct funding to be a viable choice it needs to have the same provisions that other services and supports have. Direct funding needs to be stable, portable, flexible and manageable for families. It must be available to all individuals who have a developmental disability regardless of the level of their disability. Concrete supports need to be available for anyone who chooses direct funding to access it and manage it.

Within a viable Direct Funding mechanism:

- Direct funding is portable so that if an individual moves within the province, their money follows them and can be administered in the new location. The principle of

portability also ensures that if an individual is not satisfied with a service or support they can enter into a respectful process and then freely move their direct funding allocation and purchase alternative services and supports.

- Direct funding is guaranteed over time and includes consideration for increases in living costs on an annual basis.
- It takes into consideration changes in a person's circumstances and needs on a regular basis so that the person is not placed in any further jeopardy.
- The funding allocation is flexible to adjust to variations in need and crisis situations.
- It needs to be directed at building the resilience and capacity of the individual and his/her family/friends.
- The rules for administering the funding are straightforward and easy to understand. If the rules for administering direct funding are overly bureaucratized or too complicated then individuals and families will not choose to use it.
- Individuals and their family/friends need the option of dependable, consistent and ongoing Independent Facilitation and Planning support to maximize the limited resources available.

2) Adequately and equitably funded:

Individuals who have a developmental disability, who are choosing to direct their own funding, need to have adequate funding to carry out their goals. Funding allocations must be equitable. This does not mean that everyone receives the same amount of money even though they may look like they have the same needs on paper. Equity means that people have what they need, have identified what that is and why. Appeal mechanisms need to be available to challenge funding allocations and prioritization.

Families report that some of the direct funding mechanisms that are being used now perpetuate a feeling that 'they should be grateful for whatever they get'. What they get is often woefully inadequate for providing good support. Individuals are consistently granted considerably less than what it costs to provide adequate support on a day to day basis.

Direct funding programs to date have been consistently underfunded. This underfunding of programs leads to individuals receiving inadequate funding and not being able to set goals that are individualized and aimed at creating a meaningful life in the community. Underfunding has had the “unintended consequence” of forcing individuals and their family/friends to make decisions that are not in the individual’s best interest. It has forced

those who would choose a different environment to cluster their funding and purchase supports focused on small group activities and congregate models of support.

The understating of costs also puts individuals in jeopardy because they must rely solely on their family to provide supports. This over reliance on family supports eventually puts both the individual and their family in financial jeopardy and is not sustainable over time, especially when their parents are no longer alive.

Waiting lists for funding go against equitable distribution of resources and have to rely on a fair and accurate prioritization process. Currently, there are no appeal mechanisms for challenging the equity of funding allocations and the prioritization process. This is a real deterrent for families choosing direct funding. The prioritization process must be subject to appeal.

3) Sustainable over time:

Once direct funding is granted to an individual it must be guaranteed over time unless key accountability measures are not adhered to or funding is drastically reduced for services and supports across the board.

For individuals and their family/friends to feel that direct funding is reliable and sustainable they must feel that there are limited provisions for withdrawing the funding. A three year accountability review of the funding is acceptable so long as the intention is to evaluate and refine objectives and it is clear from the outset what constitutes the withdrawal or reduction of funding.

Individuals and their family/friends currently feel tremendous uncertainty about whether their direct funding is ongoing and sustainable. This uncertainty negatively hampers planning and goal setting.

4) Promotes effective partnerships between individuals, their family and friends and those who provide independent facilitation and direct support services.

Independent Facilitation and Planning:

Individuals and their families with direct funding require the option of independent facilitation and planning support to develop/review goals and vision either within a larger context like a support circle or within the family. Individuals and families need:

- Support to take up the plan and make it happen; to “walk with the person and their family/friends over time.”

- Support to individuals and families to identify changed circumstances that impact on budget and working flexibly to accommodate these changes. This includes ensuring that funding is available 'just in time' and if spending is off the original plan, a redirection of dollars is fluid. Ensure there is an ability to redirect within the budget and write new necessities in the budget.
- Support to assist individuals to take more charge of their lives and to have more 'say so' in key decision making.
- Support to stay abreast and informed of accountability requirements of government and new resources as they become available.
- Support for negotiating supports and services and the creation of a yearly personal support agreement that sets out mutual responsibilities of individual and service providers.

Supportive Service Providing Agencies:

Individuals and their family/friends require help in maximizing and administering their direct funding resources. Policy must make provision for them to form effective partnerships with supportive service providing agencies. Such agencies must be chosen by the individual and family.

By separating the planning, advocacy, and service delivery functions, people and their family/friends enter into a working partnership each being clear of roles and responsibilities.

- Supportive service providing agencies include transfer payment agencies the person and family chooses to partner with.
- A core aim of these agencies/organizations is to assist individuals, their family/friends to self manage their direct funding in as simple a way as possible and to support them to safeguard and implement their vision for a better life.
- This includes providing highly individualized, relevant and flexible support in some or all of the following ways:
 - Support to maintain/track their budget by providing regular reports on finances and providing tracking sheets. Support to maintain financial records and receipts.
 - Assistance with preparing any reports required by government
 - Support with staffing requirements: recruitment, hiring and retention.

5) Easy to understand and interpret:

Individuals who have a developmental disability and their family/friends need to be able to easily understand and interpret the “rules of the game” as it applies to direct funding.

Policies related to direct funding must be applied fairly and consistently across the province with enough flexibility given to each of the supportive partners that individual circumstances can be factored in and provided for.

Effort must be made to give certain areas of policy clearly stated parameters that are universally applied across the province. This means that application and funding entities must create communication tools and processes that make direct funding clear to understand to “lay people” including individuals and their family/friends.

Other areas of the policy must be adaptable enough so that there is room for flexible interpretations in order to accommodate certain needs of individuals. Priority must be set for which policies can remain open to interpretation within a reasonable limit. This flexibility will assist families to administer direct funding in a way that reflects their changing circumstances in critical areas like staffing.

6) Simple to administer:

It is critical that direct funding be simple to administer.

Simplicity implies that it does not require undue paperwork and reporting requirements that are unnecessary and burdensome.

Accountability measures needs to be tied to concrete statements of goals and designed to take the individual’s changing needs into account.

7) Written and communicated in plain language:

All of the written material and social media associated with Direct Funding must be in plain language.

Careful consideration and accommodation must also be given to multi-cultural language needs, sign language and non-verbal communication supports.

8) Includes an agreement that recognizes the legal capacity of the individual receiving the funds and provides accommodation to the individual for supported decision making.

There must be a presumption of legal capacity built into the implementation of direct funding.

This assumes that individuals will be able to sign their own direct funding agreement with the support of family/friends. It also assumes that there must be accommodation provided to the individual for supported decision making.

9) Directed at assisting the individual to build a more meaningful life in their community with valued social roles and opportunities for contributing.

10) Recognizes the natural authority of the family.

It is critical that the natural authority and commitment of families not only be recognized by government but also be protected.

Family engagement varies widely in the lives of individuals who have a developmental disability however, where families are highly engaged, they should be recognized for their authority because of the tremendous responsibility they take for the well-being of their family member.

Families also have authority (normally) arising from knowing their family member the most fully and over the longest period of time. In this way they have the authority that arises from long term observation, insight and personal relationships. Families are expected to advocate for their own members. Not uncommonly, they are granted considerable presence in the decision-making processes affecting their family members, even where legal formalities do not require it.

Finally, families often have a stake in outcomes. For example, they have to live with the long-term consequences of service failures to a greater extent than any other party, except the person themselves.

Summary:

This paper has been prepared respectfully for submission to the Ontario Ministry of Community and Social Services (MCSS) which is currently undergoing transformation of their Developmental Services and is ready to take implementation further. As thoughts around policies, practices and structures with regard to Direct Funding begin to roll out MCSS is seeking input from various stakeholders. This submission seeks to outline concrete information along that vein, information that has been identified by experienced individuals, families and friends as being important.

Two of the key things shared by families were: being able to choose what transfer payment agency would flow funding and, secondly, having the flexibility to create and design what is needed for and with each person. Important was the overall goal of identifying what will make it easier for more people with disabilities and their families to act as agents in customizing the assistance they require using direct funding as a mechanism. Most important was the intention to describe what is needed to achieve a valued and interconnected life, while reducing vulnerability and increasing the choice and control over one's life. This submission summarizes what is of prime importance to making Direct Funding successful throughout Ontario.