

Community Living Ontario Policy Snapshot

Direct Funding In-Depth: Learning from New York State's Self-Directed Services

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.

For more information on Community Living Ontario's perspective on direct funding, see [Community Living Ontario's Recommendations for Direct Funding for People who have Intellectual and Developmental Disabilities](#).

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Community Living Ontario is a non-profit organization that advocates alongside people who have an intellectual disability, their families and agencies that support them across the province.

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