



Individualized Funding: Now is the Time

June 17, 2023- Inclusion Action in Ontario AGM

Individualized Funding Coalition for Ontario

What is Individualized Funding?

“Individualized Funding is an umbrella term for disability supports funded on an individual basis. Individualized funding aims to facilitate self-direction, empowerment, independence and self-determination.”

The Individualized Funding Coalition for Ontario (IFCO) has always used the term *Individualized Funding* to include the different types of funding that are individualized/personalized.

Examples of commonly used terms: direct funding, self-managed care, self-directed funding, direct payments, personalized funding, grants, individual budgets, etc.

No matter what words are used, most important is understanding that individualized funding is ***“a mechanism to provide personalised and self-directed supports for people with a disability, which places them at the centre of decision-making around how and when they are supported.”***

The above quotes were taken from the following research: Fleming, P., McGilloway, S., Hennon, M., Furlong, M., O'Doherty, S., Keogh, F., & Stainton, T. (2019). *Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review*. Campbell Systematic Reviews, 3.

Choice . . .

Self-Determination, Freedom & Control

- ▶ The **common element** for the different types of individualized funding in Ontario is about **who has the control and decision-making power for the funds.**
- ▶ The **family has control** when funds are for a child living with a disability. The **person as an adult**, with support of friends and family, would have the control. The 'family' (for a child) and the 'person' direct what happens with the funding, including how the funds will be spent.

Citizenship . . .

Community First, Inclusion - An Everyday Life

- ▶ Citizenship is at the heart of things as well as looking to community first - including where one wants to live, and what one wants to do
- ▶ Portability enhances citizenship and community inclusion.
- ▶ All citizens want this kind of freedom and control over their lives.

Individualized Funding in Ontario

The Early Days –The 80's

- 1980 **Joshua Committee**, the first circle of support in Canada was facilitated and developed by friends Marsha Forest, Jack Pearpoint, Peter Dill and others to assist Judith Snow to leave the **institution** she was living in.
- 1981 **Order in Council** for the first government mandated/provided individualized funding in Ontario enabled Judith Snow to hire her own personal attendants and move into her own apartment.
- 1982 **Special Services at Home (SSAH)** program began so children with developmental disabilities could stay out of institutions thanks to some strong family advocates who pushed for change.
- 1984 **NABORS** was incorporated with a focus on developing support networks and the principles of community, participation, self-determination. Each person supported has individualized funding.

Individualized Funding in Ontario

The 90's

- Early** **People with disabilities, parents like Gillian Chernetz, Helen Dionne, Linda Dawe, advocates, and allies like Beth French** worked together and created options that supported natural relationships, more control, for people with individualized funding and full participation for all. (CHORD, Courtyard Co-ops; Rougemount Co-op and Deohaeko)
- Mid** **Individualized Funding Coalition for Ontario (IFCO) is birthed.** Leaders in Ontario start meeting: people with disabilities, families, friends and agency allies. Over the next few years: the Accord is written, more allies, connections, & community development occurs. People, families, and allies share their stories about individualized funding, citizenship, and inclusion with each other. (This sharing with partners and allies as well continued through the decades.)
- Late** **Three individualized funding projects supported by Ministry of Community and Social Services (MCSS):** Brokerage Project (Windsor-Essex), Choices (Thunder Bay), Quality of Life Project (Toronto). All three received excellent evaluations.

Facilitation and Planning in the 80's & 90's

Planning & facilitation has always had a key part in individualized funding arrangements. Check out the words used starting in the 80's and 90's to describe planning & facilitation functions, roles that were occurring in various places, projects, organizations with among people with disabilities, families, friends & allies in Ontario.

- ▶ Circle of Support assistance
- ▶ Support Circle development
- ▶ Facilitators
- ▶ Planners
- ▶ Person-centred planning
- ▶ Maps and Path facilitators
- ▶ Graphic facilitators
- ▶ Individualized planning
- ▶ Network builders
- ▶ Unencumbered planning
- ▶ Independent planner
- ▶ Broker
- ▶ Broker/facilitator
- ▶ Independent Facilitators

The Ontario experience and international research! Common themes!

We have recognized in Ontario for many years the positive outcomes that have come about from effective individualized funding approaches. This knowledge gained as a result of: Ontario research (Lord, et al. 2006), project and program evaluations, and by listening to people and families sharing their experiences.

Recent international research (2019) has validated what we already knew:

“Well designed (individualized funding) models lead to:

- *greater flexibility in people’s lives,*
- *improved self-image and self-belief;*
- *more value for money;*
- *community integration;*
- *freedom to choose ‘who supports you’;*
- *‘social opportunities’;*
- *and needs-led support”.*

(pg. 12 in the report/Fleming et al., 2019, p. 2)



Today in Ontario we are experienced and ready. We know how to do this!

The report, *Now is the Time*, summarizes decades of work.

- ▶ Many people, families and other stakeholders have been a part of events and meetings where they have shared experiences, challenges and solutions.
- ▶ People, families, and others who participated in IFCO round tables, focus groups, learning events, planning sessions, Straight Talk days, Coffee & Conversations, and Have Your Say gatherings are in some ways ‘co-authors’ of this paper.
- ▶ The paper represents what IFCO heard from ‘people, families, & allies about what works and what doesn’t.
- ▶ It represents the best practices, experiences and research we have shared and collected. It gives us a big picture.

What we have heard - the concerns

- ▶ People, families and others have said: things have been changing for the worse and ‘are going backwards’. They say government doesn’t seem to understand and uses our own language differently than ‘we’ intended.
- ▶ What many of us have known about individualized funding approaches - what works and what doesn’t work - could be lost as families age and our allies retire.
- ▶ It is has been hard for people and families (those younger families who haven’t experienced opportunities with ‘funding’ at an earlier age) to ‘see’ what people and families used to dream about and hope for.
- ▶ In the past, many of had a picture of what a good life of inclusion, participation and contribution would be with the assistance of individualized funding, and we worked toward that.

Now is the time for people, families, and trusted others to hold onto their vision for a good life, being included and contributing . . . put forward an individualized plan or proposal for what is needed!

What we are hearing - the optimism

- ▶ People, families, independent facilitators, partners and allies are telling us they are interested in being part of a positive future with individualized funding. Hope for the future keeps growing!
- ▶ Many who have experienced individualized funding approaches over the years have shared what works. The Now is the Time paper has captured that. IFCO continues to listen and learn!
- ▶ We have had a picture of what a good life as a citizen means with inclusion, participation and contribution. Let's share it!
- ▶ Having a good life and being a full citizen is NOT just about funding! Yet, having funding to live one's own unique life helps people to take up their full citizenship!

KEY MESSAGES



HIGHLIGHTS from *Now is the Time*

What folks are saying is important to them:

- ▶ To have an everyday ordinary life full of purpose. To have as many TYPICAL opportunities as possible with home, work, leisure, and volunteering in the places and spaces where ALL citizens go.
- ▶ To have ways for people to be supported with their decisions.
- ▶ To have support for building and working on relationships from an EARLY AGE and THROUGH ADULT LIFE.*



**The key to providing seamless supports lies in the beginning and planning when a disability is first identified and . . . continuing that planning throughout the individual's lifetime. Also important is not having to deal with so many different strangers in the system – being able to develop this keep relationship over time with one person!*

“This necessitates access to unencumbered planners / facilitators to encourage the individuals / families / support networks to dream without previously constructed barriers hindering them. . . .Independent planning must be separate from service provision.”

*Transformation and Disability Supports,
The Role of Individualized Funding, IFCO, 2004.*

FEATURES of an Effective Individualized Funding Framework

TOP THREE FEATURES AS VOTED ON BY PARTICIPANTS . . .

- ▶ Having enough funding (80%)
- ▶ Someone (like an independent facilitator) that walks alongside over time, assists with planning and taking actions. (63%) *Note: this means someone working outside of direct service agencies AND central access places.*
- ▶ Support with finding, contracting and keeping workers (41%)

OTHERS IN ORDER OF VOTING PRIORITY. . . .

- ▶ Receiving some funds in advance to be able to pay workers
- ▶ Guidelines for using funding that make sense for a typical life
- ▶ Portability: being able to move your funding
- ▶ Simple ways to invoice and get the money back quickly



Now is the Time: Keys to an effective individualized funding framework AND for living a full life as an everyday ordinary citizen:

*Respect for making contributions and choices as a citizen
Having relationships, networks of support, and social connections
Control over funding and support for decision-making*

Elements:

- Individualized funding as a **viable choice** that can be counted on
- Having **enough funding** for a meaningful life
- **Portability of funding to ensure choice:** if wanting to move within the province, and/or move funds to a different transfer payment agency
- Recognizing legal capacity, and **supports for decision-making**
- **Flexibility for changing needs and for using funding**
- **Processes and/or supports that:**
 - Are easy to understand and self-manage
 - Ensure low-cost administrative support
 - Offer support for recruiting and contracting support workers
 - Provide funding advances to be able to pay workers
 - Accountability requirements that match goals
- **Citizenship rights and support for making decisions and choices in life**
- **Independent Facilitation** free of conflicts of interest (e.g., direct service, access, etc.)
- **Separating functions to ensure and enhance freedom and change**

Actions on the go

*The way to right wrongs is to turn
the light of truth upon them*

Ida B. Wells



What we have done collectively!

- ▶ Made more changes to the IFCO website to make it easier to choose an action.
- ▶ Some folks and groups have become members of IFCO since the March 2013 Call to Action.
- ▶ Volunteers came forward to help others write their stories.
- ▶ Held a gathering for story writers with tips and ideas for supporting others with their experiences.
- ▶ Presented at the OASIS Conference. OASIS, Ontario Agencies Supporting Individuals with Special Needs, is a provincial organization whose members are agencies that support people with disabilities.
- ▶ Held a Story Sharing Gathering to assist people and families to tell their stories.
- ▶ Developed a proposal for presenting at the Community Living Ontario (CLO) Annual Conference.
- ▶ Have had requests and conversations about partnering with others.
- ▶ Will be presenting at the Inclusion Action in Ontario (IAO) Annual General Meeting. IAO focuses on inclusion and education issues in Ontario.
- ▶ Have provided information about supports for decision making and what we can do to avoid guardianship on our website.

More Opportunities for action and being a part of things

- ▶ Consider a review group looking over previous government documents and findings, some examples:
 - ▶ Select Committee on Developmental Services, Final Report (2014), Nowhere to Turn (2016), Housing Task Force Final Report (2018) etc., Auditor General Reports, etc.
- ▶ Seeing what IFCO has learned about what feels safest for people and families in sharing their experiences/story telling.
- ▶ Being supported to share your experience anonymously with the help of a volunteer - someone who will listen and write things down for you



**Things to take with you after
this gathering . . .**

**Quotes from *Now is the Time*
and links for the journey**

Building conditions for people to stay strong

From the 2022, report *Power and Connection: The International Development of Local Area Coordination*, authors Eddie Bartnik and Ralph Broad identified that:



“Now more than ever, it is time to look at how, together with local people, communities and services, we can build the conditions for people to stay strong, safe, connected and valued as active, contributing citizens and to rebalance our limited resources towards a greater focus on individual, family and community, capacity building and mutual support.”

(Now is the Time, p. 14)

Support with relationship building, shifting the power dynamics, having a voice

“People are much more likely to maximize their use of individualized funding when given support (facilitation and planning) with relationship and network building, shifting the power dynamics in their life, strengthening their willingness to become known by others and have a voice in their life and in key decisions.”

Now is the Time, Pg.14

Supports for decision-making

One of our most talked about topics

“Ontario needs legislation that honours supported-decision making.”

Ontario needs a way to ensure:

“Support for decision-making and that each person has the capacity to express their will and their preferences in some way. (That they) can be involved in directing their life and taking charge of key decisions with the support of others”.

(OIFN, 2022, What We Believe section, para.3)

Now is the Time, Pg. 13



Thank You for your valuable time!

Individualized Funding Coalition for Ontario: <https://individualizedfunding.ca/>

Now is the Time: [Use this link to download the IFCO report, Now is the Time](#)

ACTIONS page: <https://individualizedfunding.ca/actions/>

Membership Links:

- On-line Membership Form:
https://clw.formstack.com/forms/ifco_membership
- Brochure: [IFCO Information & Membership Brochure, 2023](#)

More Actions and Ideas (a work in progress, check regularly for updates):

<http://individualizedfunding.ca/more-actions/>

Legal Capacity and Supported Decision-Making:

<https://individualizedfunding.ca/action-needed-for-ontario-citizens/>

Learn more with this PowerPoint: ['About Individualized Funding-Fall 2021'.pdf](#)

