

Enhancing Choices, Relationships, Citizenship and Community Inclusion with Individualized Funding



*Guess what? . . .
Individualized Funding has
been here all along!*

Let's build on what we know, expand opportunities, and create additional capacity together. **Now is the time!**

Presented by:

Individualized Funding Coalition for Ontario

in collaboration with . . .

Family Alliance Ontario (FAO),
Ontario Independent Facilitation Network (OIFN),
Inspired by Our Grassroots, Resources & Capabilities Committee,
and Community Living Ontario



Many thanks to the IFCO Leadership Team and IFCO Ad Hoc Planning Group for all their hard work: Yona, Kory, Betty, Joyce, Michelle, Vici, Colleen, Melodie, Janet, AND to Judith (consultant) and Shawn (partner). A huge thank you to the people and families who have shared their experiences, provided direction, and who have supported and validated the work of IFCO . . . before, during and following the pandemic.

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Choices, Relationships, Citizenship, Inclusion

Introducing our team of presenters

Kory Earle, Past President, People First of Canada,
Co-Chair, Individualized Funding Coalition for Ontario (IFCO)



Image provided to IFCO by Kory

- ▶ **Betty Daley**, Parent, Provincial Family Leader,
President, Family Alliance Ontario (FAO)
- ▶ **Colleen Mitchell**, Independent Facilitator/Broker,
Leader, Ontario Independent Facilitation Network (OIFN)
- ▶ **Melodie Cook**, Grandmother, Retired Executive Director,
Chairperson, Inspired by Our Grassroots, Resources & Capabilities Committee
- ▶ **Shawn Pegg**, Director of Social Policy & Strategic Initiatives,
Community Living Ontario (CLO)

Individualized Funding Coalition for Ontario (IFCO)

Our Accord

The Individualized Funding Coalition for Ontario supports the self-determination of persons with disabilities.

We believe that all people should have control over decisions concerning:

- where they live,*
- with whom they live,*
- with whom they associate, and*
- how they spend their lives.*

In order to achieve this, we recognize that Ontario must develop funding systems whereby the person requiring assistance, supported by family and/or significant others, has access to and control over the funds allocated for their supports.



Choices, Relationships, Citizenship, Inclusion

What is Self-Determination?

Tom Nerney – Defining Self-Determination

Tom Nerney explains self-determination and the restoration of citizenship from 3 levels: personal, organizational, and political. He cites 4 universal human aspirations important to focus on: a place to call home, community membership, relationships, and work.

<https://www.youtube.com/watch?v=fBMzCCKEuss>



'After the conference bonus video' for those interested in more information about changing systems for people living with developmental/intellectual disabilities: Tom Nerney, Director of the Institute for Health Quality and Ethics at the time, presented at Claiming Full Citizenship an international conference held in Vancouver, October 2015. He spoke about the evolution of self-determination based supports and services in the United States and argues that people with disabilities will not achieve full citizenship without the adoption of quality standards based on universal human aspirations. 'State of the Nations'. a video by Rights Based Social Policy: <https://www.youtube.com/watch?v=ptOofXCeVLw>

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What is Individualized Funding?

As defined by IFCO

Individualized Funding Coalition for Ontario (IFCO) describes *Individualized Funding* as government funding that is used to purchase disability related (and/or health related) supports. A few examples: paying for a support worker, a personal attendant, and/or other approved items or services

IFCO has always used the words *Individualized Funding* for all the different types of funding that are allocated or designated for one individual. Examples of other common words/names for funding include:

- ▶ direct funding,
- ▶ self-managed care,
- ▶ self-directed funding,
- ▶ direct payments,
- ▶ personalized funding,
- ▶ individual budgets,
- ▶ family-managed home care, etc.



An important feature that is common to every type of individualized funding: people have more freedom and choice as the person receiving the funds is the director, the decision-maker (not the agency holding the funds).

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Choice . . .

Self-Determination, Freedom & Control

Who directs? Who has the control and decision-making power for use of their individualized funding?

When funds are for a child living with a disability the **FAMILY** makes the decisions. For example, with Special Services at Home funding families decide how funds will be spent within those guidelines.

As an adult living with a disability, the **PERSON**, directs with their choices and has decision-making power for their funds/funding allocation (with the support of family and/or trusted others as needed.)



Listening to the person, their goals, interests and desires for life helps tailor their supports to their everyday life at their direction. It is an ongoing evolving process.

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Citizenship . . .

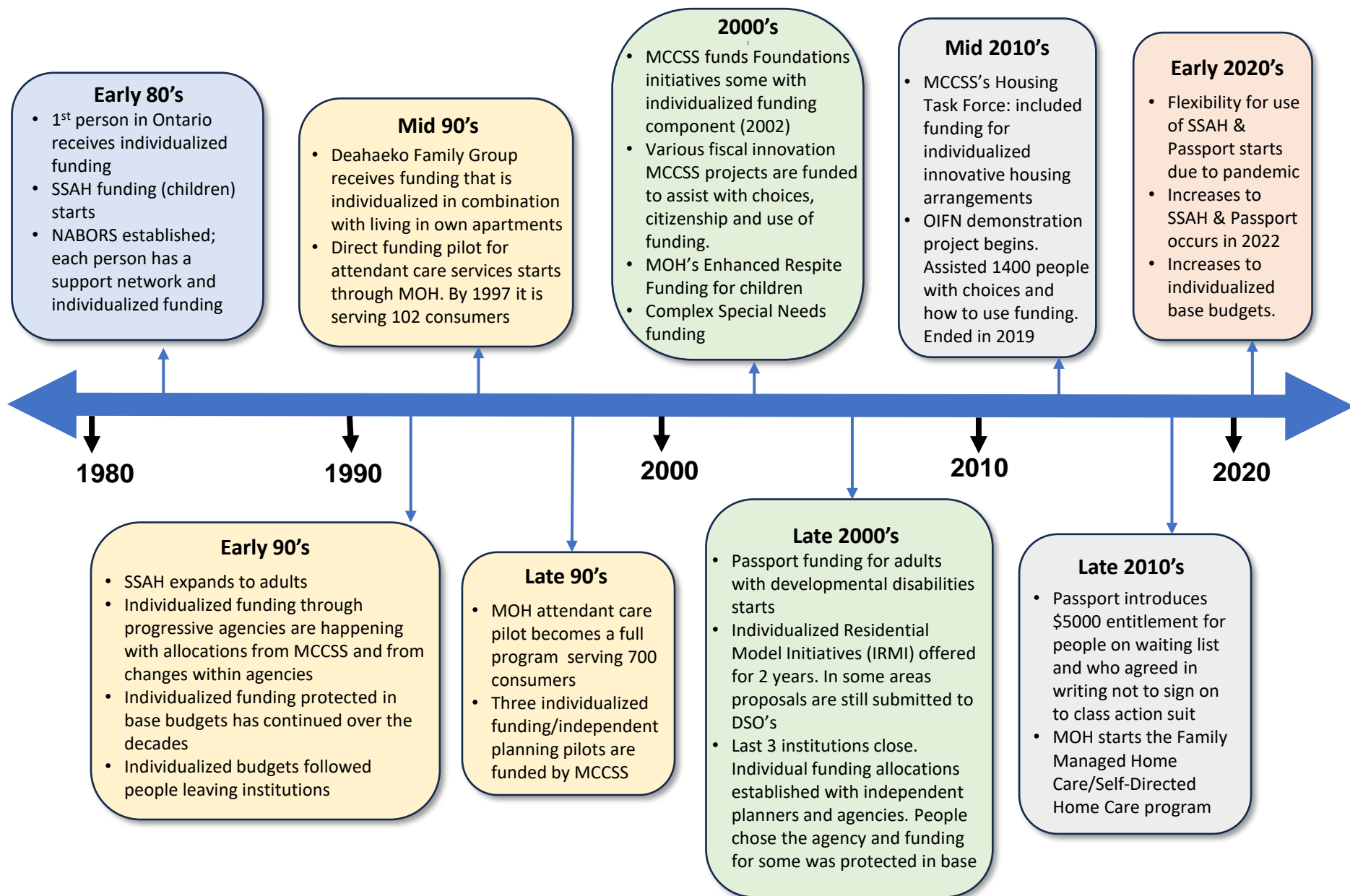
Community First, Inclusion, An Everyday Life

- ▶ Citizenship is at the heart of things. Individualized funding helps people with full citizenship.
- ▶ IFCO believes in the principle of looking to community first for typical places and things to do just like other citizens do.
- ▶ For example: What interests me, what do I like to do, where can I volunteer, where do I want to live?
- ▶ All citizens want this kind of freedom and control over their lives. That is what self-determination means.
- ▶ Portability of funding and choosing where one would like to flow their funds enhances choice and freedom for people well.

Individualized Funding and the key features that go along with it are not new! Before we go any further let's look at our own history in Ontario!



Timeline for Individualized Funding in Ontario as it evolved



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International Review

Individualized Funding as defined by international researchers

“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.”*

Individualized funding (no matter what words are used) 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., Herson, 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.

International Review . . .

Published in 2019, examples were studied over a 24-year period

For the purposes of the review any form of individualized funding was studied regardless of the name given IF IT MET THE FOLLOWING CRITERIA:

- ▶ **Funding provided by the state (government)** as financial support for people with a lifelong disability (physical, sensory, intellectual, developmental disability or mental health)
- ▶ Individual was able to **freely choose how this money is spent** in order to meet their individual needs
- ▶ The individual **could use 'intermediary' services** or the equivalent that supports them in terms of planning and managing how the money is used over the lifetime of the funding
- ▶ The recipient **could also choose to independently manage** the individualized fund in whatever way is feasible
- ▶ May be a **one-off pilot** intervention for an individual (minimum of 6 months) or a **permanent move from traditional forms of funding arrangements**

**See citation on the previous slide*

International Review . . .

Includes this study from Ontario done for IFCO in 2006

Moving Toward Citizenship: A Study of Individualized Funding in Ontario

Principle investigator, John Lord. Four projects/sites from Ontario were chosen; 130 people with developmental disabilities and their families who used individualized funding from 2001 – 2005 were part of the study. This study demonstrated that costs for individualized funding may be similar to conventional supports, but quality of life outcomes are usually much better. Facilitators at all four sites played major roles in the lives of individuals and their families. All families were very positive about the importance and helpfulness of their facilitators.



(Lord, Kemp, Dingwall & Hutchison, 2006)

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International Review . .

Ontario experiences validated by international research!

We have recognized in Ontario over the years that the following positive outcomes have come about from effective individualized funding approaches. This has been demonstrated through the Ontario study (Lord, et al. 2006) AND many other projects, program evaluations, and in listening to people and families share their experiences. The international research from 2019 has validated this as per this quote:

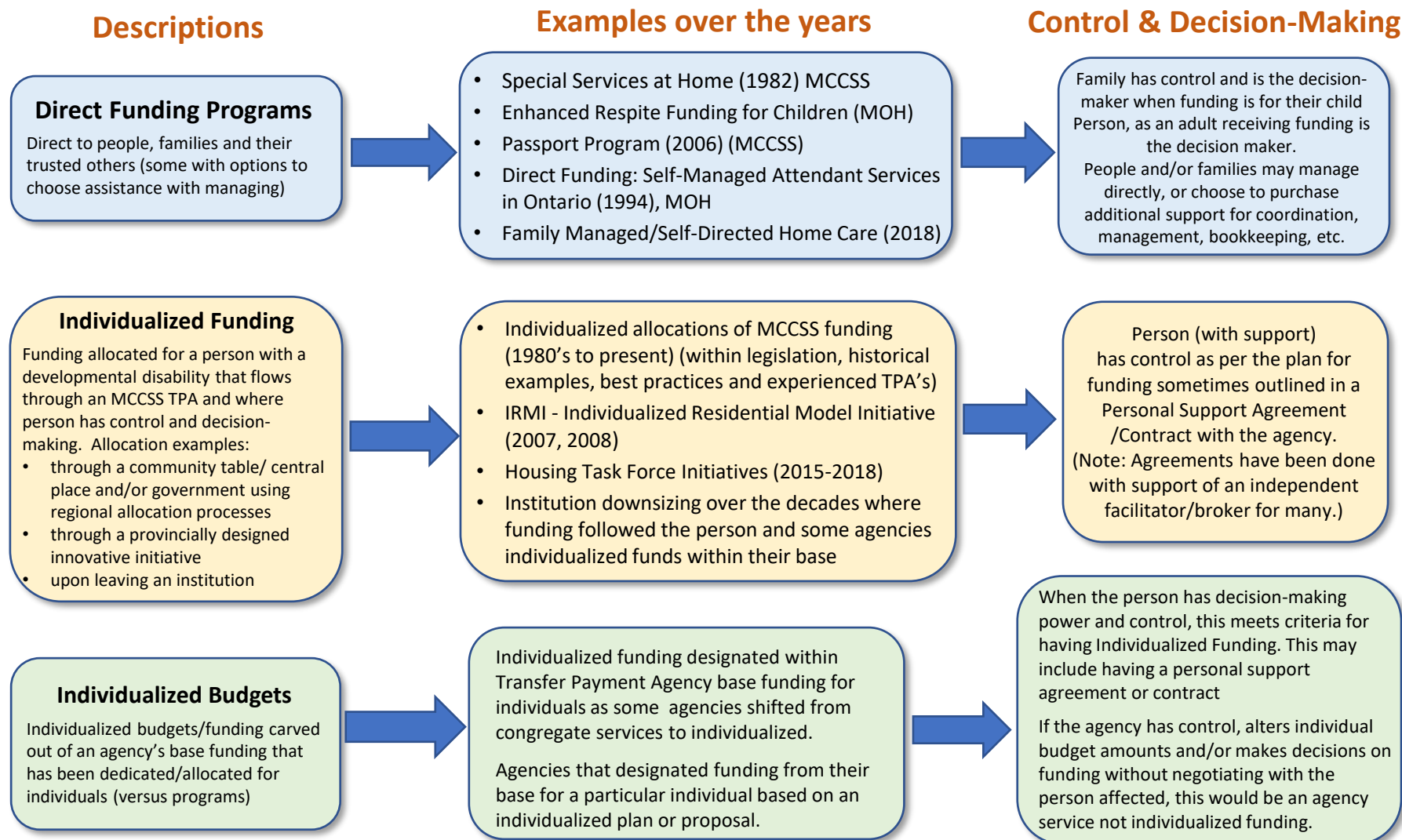
“Well designed (individualized funding) models lead to:

- *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”.*



Individualized Funding in Ontario – Spanning 4 Decades

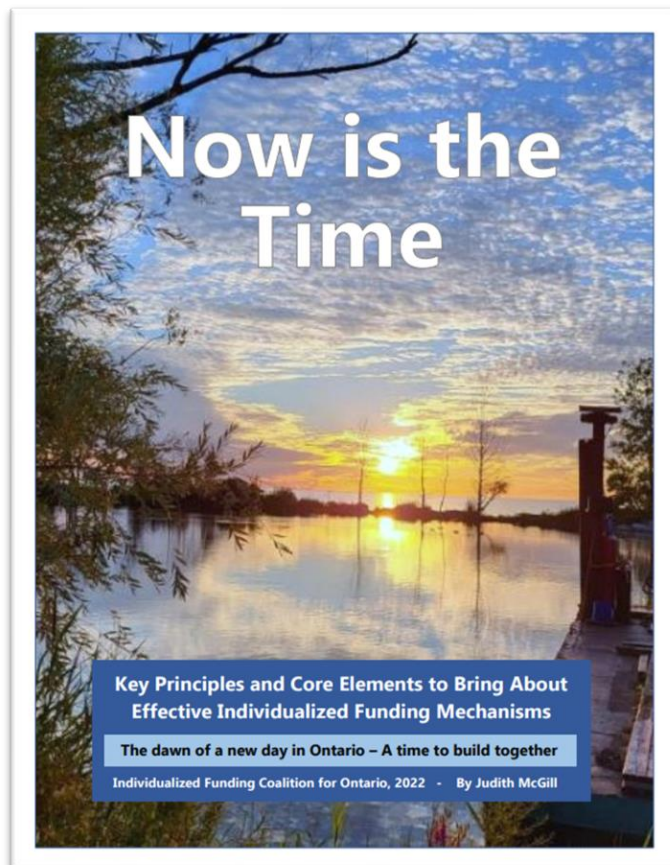
Spanning four decades in Ontario: Examples where people and their families and/or trusted others have had control of decision making for their individualized funding. Funding used to purchase the supports/supporters they need to participate, be included and contribute in, their neighbourhoods & communities. In some situations, they also choose how much they want to self-manage or coordinate things or not.



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Now is The Time ... An IFCO Report

What we know and have learned over the decades. . . .



IFCO image

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

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Highlights from *Now is the Time*

What folks are saying is important to them:

- ▶ 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.

Starting Early . . .

*When a disability is first identified, providing seamless unencumbered facilitation support **early** is essential. This encourages and supports individuals / families / friends/ support networks to dream, envision their future and overcome 'barriers'.*

It means:

- *Having access to independent facilitators early in life and continuing to receive that support throughout a child's/person's/ lifetime.*
- *Not being expected to connect with numerous different coordinators/ support professionals for coordination and case management as a child.*
- *Consistent relationships build trust.*

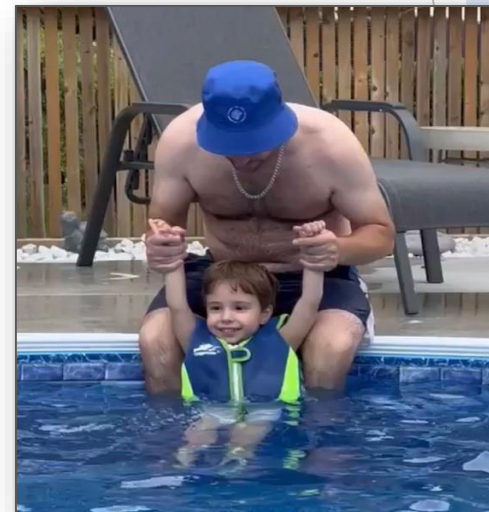


Image provided by IFCO member

Features of an Effective Individualized Funding Framework from *Now is the Time . . .*

Top three features as voted on by IFCO participants in Spring 2023:

- ▶ 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%)

Other features 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



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Now is The Time ... An IFCO Report What we know and have learned over the decades. . . .

Elements of an individualized funding framework . . .

- 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**
- **Separating functions to ensure and enhance freedom and change ... full citizenship**

Moving to Full Citizenship with More Choice and Control:

Being able to choose a separation of functions

Independent Facilitation & Brokering

Facilitation, planning and brokering that is separate from and independent of: direct service provision, people's funding, and the system's access/application entities and the allocation of funds.

Person directs. Leads to strengthening the person's voice, the capacity of people, families and support networks, and to more community participation and contribution in everyday life.

Advocacy / Autonomous Groups

Advocacy and support: peer-to-peer/family-to-family support by people, families and/or trusted others and autonomous groups. Examples: People First Chapters and Family Networks/Groups autonomous of agencies and systems, and Support Circles, etc.

Offers leadership in innovation and education; peer support; advocacy; provides a balance in the system and can safeguard new approaches with their voice.

Services and Supports

Entities/structures/agencies that provide coordination of human resource support, financial accounting, etc.

Personal, home and community supports and services through independent contractors and/or service providing agencies.

Person (with others as needed) decides where to purchase their supports and services (e.g., from the community at large, service providing agency, etc.

Access and Allocation

Systems structures/mechanisms for determining Eligibility, doing Applications and Assessment, and Allocating funding at a designated entity and through government processes.

Note: Developmental Services Ontario (DSO) is currently the system's mechanism for entry into Adult Developmental Services.

*Moving toward full citizenship with more choice and control for 'all' with the option of separate functions for: facilitation and brokering, application and allocation of funds, direct service, and peer support and advocacy. This framework is different than a more traditional one where all/or many of these functions have historically occurred within one direct service providing agency or system access. With an individualized funding approach, having the option to: 1/ have facilitation and brokering separate from the systems, 2/ connect with autonomous 'peer' groups, and 3/ purchase direct supports as determined by the person with family and trusted others - **leads to more choice and control!***

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Independent Facilitation*, Planning & Brokering AND Individualized Funding together

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

*“People are much more likely to maximize their use of individualized funding when given **support*** 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



**Note: Other jurisdictions/places around the world have different names for ‘independent’ facilitation and the type of support provided. Some examples: unbiased personal planning; conflict free brokering/planning/coordination; unencumbered facilitation, etc. The common theme for this support is that the roles are free of conflict of interest from other functions/roles/organizations in the system.*

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Independent Facilitation, Planning & Brokering

Important features of independent facilitation are that: it is free of conflicts of interests from direct supports/services and central access points, AND it is an ongoing process that supports people to create change. Through conversations, over time, ideally from childhood to adulthood, people, their families and/or trusted others are supported to:

- *Imagine possibilities,*
- *Make their own choices with good information,*
- *Reflect on learning and new possibilities as they come into their adult lives and experience life transitions,*
- *Think about, plan for and take action steps toward creating the ordinary, everyday lives that they want in their chosen neighbourhoods and communities,*
- *Tell their stories.*



Vision to Actions and Back to the Vision!

People work hard, with others they trust, as they explore next steps in developing a meaningful life.

<https://individualizedfunding.files.wordpress.com/2022/02/from-visions-to-actions-dec22021.pdf>



Readiness and moving forward: People are active in the planning and evolution. Sometimes the person is ready faster than their parents or the work that needs to be done; it can feel slow.



People and families look to the future with a **vision** to live and contribute as everyday, ordinary citizens in their neighbourhoods and community.

Everything cycles from and back to their vision of life as an everyday, ordinary citizen.



Thoughts are shared even before they are shaped. Ideas and possibilities evolve through conversations and listening to the person as their voice is strengthened.



Families have work to do in between. With regard to housing it could be exploring the community, speaking with municipalities, funders, service providers, financial lenders, lawyers, etc. The pieces start coming together.



An independent facilitator/broker walks with the person and their family assisting with the conversations at a pace the person directs and finds safe. Questions are explored together like: What would make a home "my home"?

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Independent Facilitation, Planning & Brokering

People thrive on access to dependable, consistent and well-trained independent facilitators who are conflict free. They support people to:

- *strengthen their voice,*
- *share their wants, needs and gifts,*
- *work toward their visions of a promising future.*

As things evolve independent facilitators support people, families and trusted others to talk about changes so that next steps reflect the person's current wishes, preferences and visions for their lives.

Community Development and Valued Roles

Independent facilitators have an important role to play in changing communities and community development one person at a time. They help pave the way and open doors to valued roles, living out passions, and getting more connected!

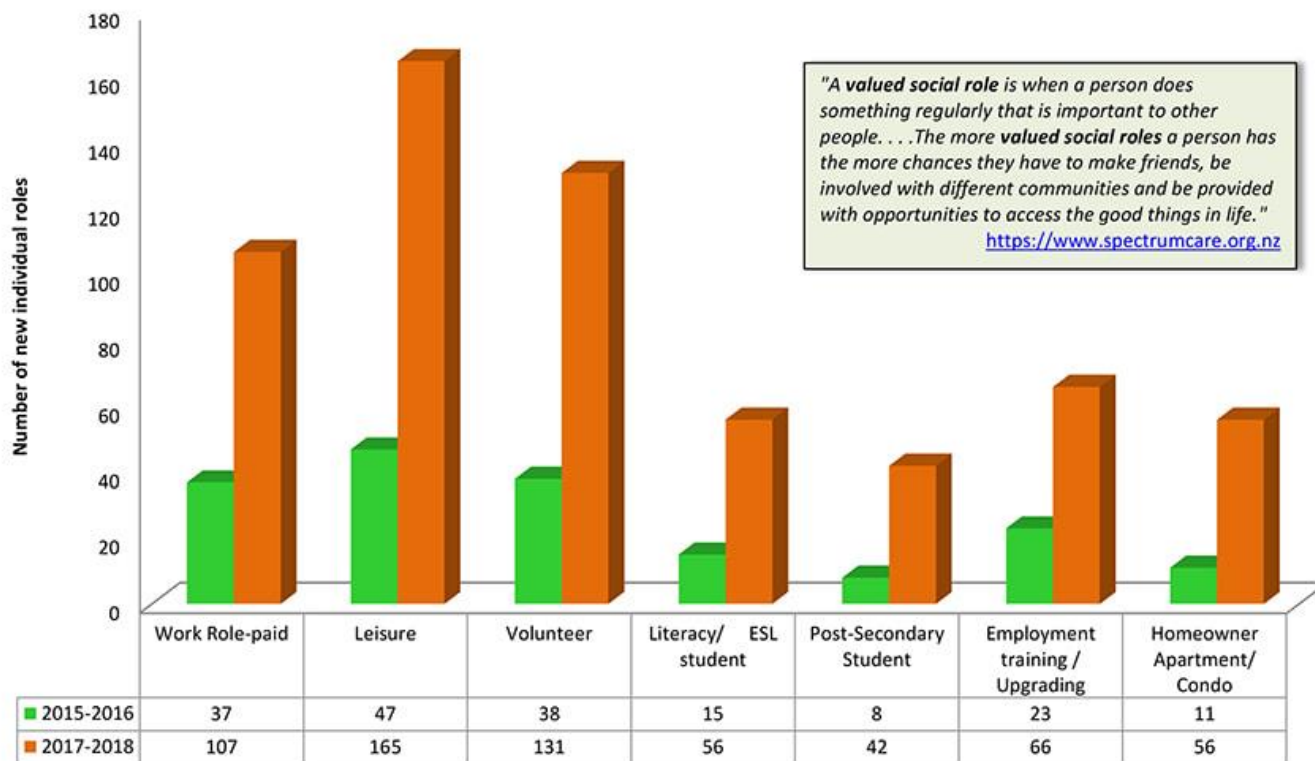
Information on the last 2 slides has been adapted from information on the OIFN website.

“Building trust with a facilitator and ‘walking with’ is critical.”

Impact Slides: EVERY DAY LIVES & ENGAGEMENT

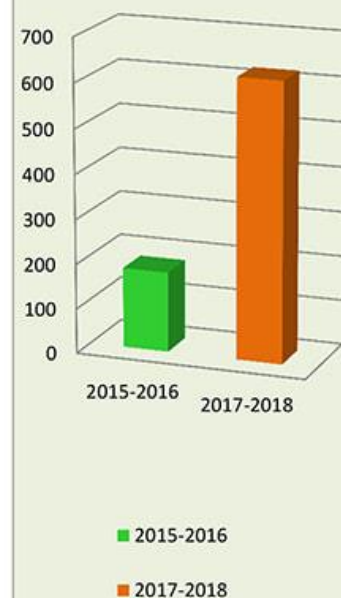
Independent facilitators supported people to take up new valued roles (this slide) and becoming engaged in more actions (next slide)

New valued social roles taken up by people participating in the OIFN project - a demonstration of growth and impact over time

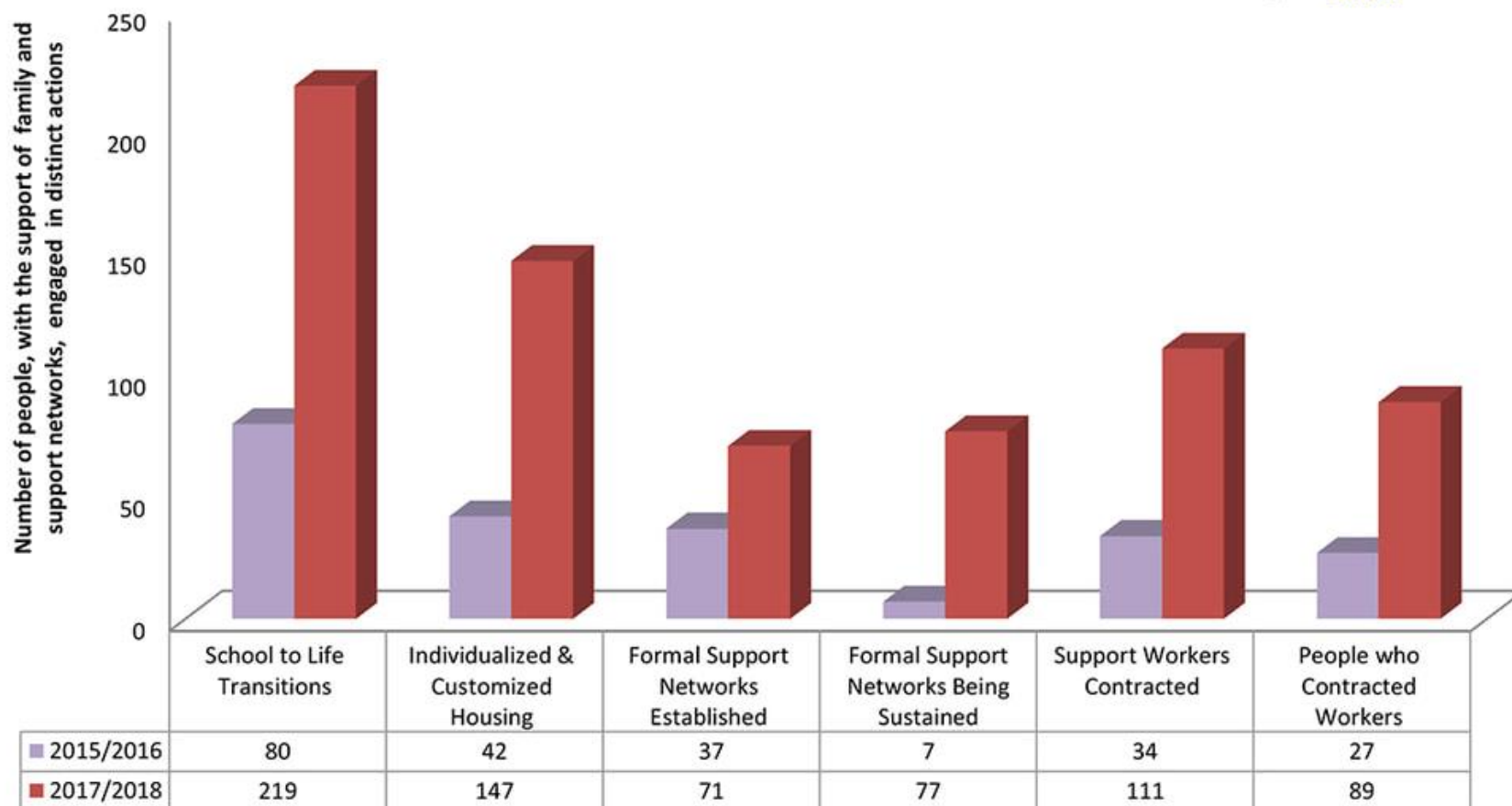


"A **valued social role** is when a person does something regularly that is important to other people. . . . The more **valued social roles** a person has the more chances they have to make friends, be involved with different communities and be provided with opportunities to access the good things in life."
<https://www.spectrumcare.org.nz>

Total number of valued social roles taken up



Independent Facilitation, Support for Engagement in Actions



© OIFN - Independent Facilitation Support – 2015/2016 & 2017/2018 – Collective Impact Data

Note: The work for the first year of the OIFN Demonstration Project regarding Independent Facilitation began summer/fall 2015. By fall each organization was starting to meet with people who were being referred by their respective DSO's. While data from the first year of the project and the third year are provided in this chart, the purpose is not to compare, but to demonstrate the growth and the impact the support of independent facilitation has over time.

Sharing of Personal Story at the Conference

Questions & Thoughts for Participants

For stakeholders who are interested in making some changes including: options for separate functions; having a shared vision, values and principles for your area/community; and/or different responsibilities and roles among people, families and partners . . .

We hope that some of the following questions will assist you on your path:

- *Are there people and families in your community who would like to see an individualized funding framework, one that includes: some independent facilitation and planning, and user/friendly infrastructures?*
- *Are there people and families who would like an everyday life with the support of individualized funding, but have had nowhere to make such a request OR who have asked for this and been told it is not possible?*
- *What could you do to assist a person (and their family or network) who asks for individualized funding in your community? Could you explore this together?*
- *Can you see some possibilities or opportunities for building a framework that could support folks differently (in partnership with others, including people and families)? Have you considered thinking geographically?*

Questions & Thoughts for Participants

- *Is there anything you can do to start working toward a local framework in your community that might include some newer features that are ‘unencumbered’ & ‘autonomous’.* This would give people a way to have: a stronger voice; more choice and control; and start envisioning tailor-made supports for their passions and valued roles.
- *Where there is no established independent facilitation could you find a way to develop and build that capacity in your community?* The reason: So that people would have access to and not have to purchase independent facilitation with their ‘support’ funding.
- *Would you consider investing time and money?* You could start with one independent facilitator AND assist by investing in training and mentoring from seasoned facilitators elsewhere in the province.
- *Are you ready to create user/family-friendly structures to assist people with their funding?* It would mean looking at some of the obstacles and finding your way around them?
- *Would you consider reaching out to some provincial groups for new connections and/or for assistance?* You could invest in such groups by asking for and/or purchasing their assistance in your community.

Choices, Relationships, Citizenship, Inclusion

What people, families and allies are saying government can do to support change

- ***Leave the traditional system the way it is for now.*** It could be developed and evolve over time instead of re-designing the entire system at once.
- ***Commit to a system that runs parallel with friendly features, processes and mechanisms for those who would choose individualized funding.***
- ***Use the knowledge and experience in Ontario about what has worked.*** There are existing individualized funding approaches spanning more than 3 decades that have demonstrated good outcomes
- ***Co-design with those who have knowledge and lived experience with individualized funding approaches*** - people, families/trusted others, independent facilitators, agencies and grassroots orgs – many who have created processes together in the past.
- ***Create a broad user-friendly individualized funding approach*** for people and families/trusted others. This would give those who want self-determination and individualized funding opportunity to live their lives more like other typical citizens. Use the foundational values, listed in Common Vision:
 - ❖ **Citizenship**
 - ❖ **Self-determination**
 - ❖ **Inclusion and community engagement**
 - ❖ **Individual and family empowerment**

Choices, Relationships, Citizenship, Inclusion

What people, families and allies are saying government can do to support change. . . .

- ***Make changes to current system functions.*** Consider the knowledge gained over the years in Ontario through the eyes of people, families and others about what hasn't worked. Redistribute government funds to support those features and functions people have been asking for that will result in more choice and control.
- ***Begin to Separate the different functions in the system as described by IFCO.*** Ensure agencies and organizations know there is value for their different roles/functions in the system. Ensure third-party independent brokering / facilitation / planning is in place and free of conflict. Be cautious about “under one roof” models of supports.
- ***Separate the following functions as listed below:***
 - ❖ ***Service delivery***
 - ❖ ***Independent facilitation and planning***
 - ❖ ***Autonomous peer networks/groups: Family Networks and People First Chapters***
 - ❖ ***System functions: eligibility, applying for supports, assessments, and allocation (not the place for planning).***

Choices, Relationships, Citizenship, Inclusion

Back to . . . Self-determination, Choice & Freedom

People, families, friends and allies would like government to ensure there is support for decision-making in Ontario!

It is one of our most talked about topics!

People have been asking the government of Ontario for a legal way to implement supported-decision making and come in line with the United Nations Convention for Persons with Disabilities for MANY YEARS!

Ontario needs a way to ensure: *“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 (IFCO):

<https://individualizedfunding.ca/>

Now is the Time paper:

[Use this link to download the IFCO paper *Now is the Time*](#)

Building a Full Life + a Home of One's Own in the Community

<https://communitylivingontario.ca/resources/>

Learn more about individualized funding with this PowerPoint:

['About Individualized Funding-Fall 2021'.pdf](#)

A Walk Through Some History, PPT - May 2021

[Click here to download 'A Walk Through Some History'.](#)

What 24 Years of Experience from Around the World is Telling Us, PPT - May 2021

[Click here to download 'What 24 Years of Experience. . .'](#)

Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review. Campbell Systematic Reviews, 3. Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F., & Stainton, T. (2019). <https://bit.ly/3hJvxFX>



Resources for looking back at some IFCO history/work

Common Vision Partners: Family Alliance Ontario, Individualized Funding Coalition for Ontario, People First of Ontario, Special Services at Home Provincial Coalition. (2005). *Common Vision for Real Transformation*. Common Vision Partners.

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<https://individualizedfunding.files.wordpress.com/2014/07/the-round-table-report-with-current-contact-info.pdf>

Thank You!

To check out more resources go to our website:

<https://individualizedfunding.ca/>