

A Message from the Individualized Funding Coalition for Ontario

Fall News Brief - September 2021

Reflections: Past and Present



The Individualized Funding Coalition for Ontario's Leadership Group has had some good conversations and gatherings over the last few months with: people and families; independent facilitators, partners and allies; executive directors and provincial leaders, and the Ministry of Children, Community and Social Services (MCCSS). Many thanks to the leaders who have helped us - you know who you are! It has been a busy and very productive time.

For many of us, it has also been a time of remembrance. Given all that we have seen and experienced in the last months, we are also remembering key leaders who have passed away. As we wrestle with this new environment where hopes for social justice and pro-active reform abound, those who worked with the Individualized Funding Coalition for Ontario (IFCO) for change are being deeply missed.

Malcolm Jeffreys, Judith Snow, Peter Dill, Beth French, and Richard Ruston are names that keep coming up as we reflect about what IFCO accomplished and learned because of each of these amazing leaders. Their courage, innovation, commitment, and wisdom were predominant within 'our' movement to enhance citizenship, self-determination, inclusion, and the use of individualized funding to increase choice and control for people living with disabilities. Their names continue to be mentioned as we collectively think about ways to work together at moving individualized funding into the future.

These leaders had an integral part in the positive change that happened within Ontario - through the 80's, 90's, and the early 2000's. We would now call it 'major change' in looking back - change that led to many people able to:

- choose lives as full citizens,
- be in control of their funding and their supports,
- choose their relationships paid and unpaid,
- live in their own home option with supports, and
- follow their passions on a day-to-day basis.

Over time, such change hasn't occurred in every part of the province. We can still say that Special Services at Home funding continues to be the first learning ground for young families with regard to self-directed individualized funding. And there are now other funding programs in place for children, adults and seniors. However, families have shared that some offer limited amounts of funding or have too many restrictions. In one program funded by the Ministry of Health, families report that the guidelines could result in stripping people with disabilities of their basic human rights. This has families and allies worried.

We know that the earlier years of innovation have been stalled for awhile now. But the good news is that there are current examples and pockets around the province that can bring hope and knowledge into our future planning. What does having these pockets mean? Having them means there is a collective "we" made up of different stakeholders with long-time, lived experience who know how to successfully do this!

MCCSS is talking about individualized funding in their reform document. This could be a good thing, as we frequently hear from people and their families living with disability and/or complex medical needs that they would like adequate, flexible, portable, individualized funding, and the option for independent facilitation.

This would mean in part funding a person controls that supports them to live a good life just like other citizens on their 'block'. Independent facilitation, a third-party option, to support and strengthen a person's 'voice and choice' for an everyday life. Citizenship and what that means is everything! Let's not lose hope as we reflect on the wisdom of those who passed away, and that of other leaders who have also greatly contributed and still play a part in change. Let's not lose hope as we continue to do the work that leads to a future where individualized funding is a robust and authentic choice in Ontario.

Younger Families and Others Want to Learn

The 'Coalition' is getting requests to help younger families and others understand what individualized funding is and what it means for people's lives. These requests are coming directly from families at events and from family groups. We have also received requests for speaking at various learning opportunities. From the AGM at Windsor-Essex Family Network in June, to our own IFCO gatherings over the summer, to the FAO Family Knowledge Share late September and another group event in early October. We continue to respond to the comments that arise from these gatherings. It is important as we continue some of the more strategic work we have planned, that we are also hearing from people and families.

Coffee & Conversations Virtual Gatherings 2021

We recently hosted two virtual Coffee and Conversations gatherings, one in August, and a second one September 15. There was a great deal of interest in the events with over 40 participants – people, families and partners - sharing in some vibrant and timely conversations. Some of the participants were seasoned and experienced with individualized funding, others were there to learn more. Many thanks to those partners/professionals who came out and added richness to the conversations and who were able to respond to some of the questions posed by families. To read more about this see the Appendix included with this Newsletter, *A Summary for You!*





Have Your Say! October 4, 2021, 1:30 - 3:00 pm

The ***Have Your Say*** virtual event has been designed for people with a developmental disability who are using and/or are waiting for funding supports through developmental services. It has been especially difficult for people living with disabilities during the pandemic. This is a gathering for people to share about their day-to-day supports and whether things have changed since the pandemic. It is also a chance for people to say what they would need for a good quality life into the future.

The event will be facilitated by Kory Earle. Kory is a member of the leadership team with IFCO. He is also currently the President of People First of Canada. For more information, you can read about this event in the Appendix. Check out the flyer attached with this email to learn how to register. Share the flyer and information with someone you know who would like to attend, and if they need assistance, please help them get registered. Or go to the IFCO website home page at <https://individualizedfunding.ca/> for the event information and the registration link.

What We are Hearing; Concerns & Confusion



Families, allies and partners, who have long-time experience with individualized funding and the other features of a good life written about for years, have been expressing their concerns at various IFCO gatherings, planning meetings and discussions. Concerns include: 1/ possible next steps with developmental services reform in Ontario AND 2/ what people, families, agencies and allies are seeing happen in real-time. By addressing concerns, it could bring a bit more hope to the conversations. Below are some of the questions and comments, followed by ideas and suggestions:

- Q** *“Is it possible the MCCSS reform process could include new programs or pilots that are led by an agency that does not have the experience with individualized funding? For example: somewhere that the vast majority of their supports have been in group settings, where individuals and families were not able to direct/control their funding and supports?” “That would be confusing, and worrisome. This approach is not something that can be implemented without having lived the values and practices established over the years.”*
- Q** *“We know of some large agencies who are talking with the people they support about what programs they would like to see.” “Some agencies are getting ready to provide various options from the top down, a menu of sorts.” “That arrangement would be difficult for my family member who wants more control of his life and to be involved in his neighbourhood with individualized funding for supports.” “Citizenship to us means starting from the bottom up, with our family member directing, controlling, and creating with assistance.” “Does our government think reform means having agencies leading and people and families choosing from what they are offering?”*

There are lots of changes going on within agencies, especially regarding how people spend their day. This is not, however, the same issue for people who would like individualized funding to look to community first and be supported. Because concerns are being raised, and MCCSS is referencing individualized funding in their reform paper, it will be important for IFCO and other allies to present a recommendation to the government. One suggestion: That any new direction/program/pilot regarding individualized funding for a whole life be led by a collective of experienced stakeholders. Stakeholders who: have lived experience with individualized funding over many years, understand what it means, how things can work, and have already learned from trial and error. Credibility and confidence in change is important; various agencies, allies, facilitators, people and families have figured things out together over the years.

- Q** *“Does our government understand what is meant by self-determination or self-direction, and the importance of supported decision making as a human rights issue?”*

It will be important to share stories that have effectively engaged and closely listened to people being supported by families and others in their decision-making process - again lived experience will be key. Stories that can illustrate how much a person’s voice matters, and that with the help of their families and others, they can direct their life choices, funding and supports, and how much confidence that brings.”

We are frequently hearing about the disappointment that there is still no mechanism in Ontario to support a person’s decision-making and have it legally recognized. There is a great deal of anxiousness around having to get guardianship of sons, daughters, sisters and brothers. This is something that goes directly against what the UN Convention for Person’s with Disabilities states.

- Q** *“We are receiving conflicting messaging from Developmental Service Ontario offices in different regions. Some assessors will let families put into their application that they want individualized funding, or individualized residential funding. Other assessors are saying “No” to such requests, stating it doesn’t exist. How can this be so different region to region? What can we do about this?”*

This issue is not new to IFCO, but it has again come up in recent meetings and gatherings. It was well expressed at our Coffee and Conversations gatherings by families from different parts of the province. Please read the Appendix, called *A Summary for You* to see what suggestions came forward at this virtual gathering in September. See also, the attached document called *Year in Review, DSO Central East Region*. It summarizes the data collected over a year, including how many people have requested individualized residential funding, which demonstrates that this option can be requested.

Q “What do we do when there is no transfer payment agency in our area that is willing or able to flow individualized funding for us?” “We would like to move our funds to an agency that has people and family friendly practices with individualized funding, but don’t know what to do? Is portability still a feature of individualized funding?”

Portability of funds has always been a recommended best practice by IFCO and allies. Some regions of the province have supported choice for individuals and families, and with the help of a facilitator, have moved money and adjusted contracts within their regions. There have also been examples of funds flowing to other regions in the past. We are hearing from families and allies that portability has been more difficult. As we work on a simple approach to individualized funding and collaborate with others, IFCO would be supporting portability as a key feature.

Q “How do we dispel the myths that individualized funding will cost less than other supports?”

IFCO’s research and other research documents have noted that individualized funding doesn’t always cost less, that it is generally **cost neutral**. Most significant is knowing that individuals and families identify that their quality of life, and personal satisfaction, health and well-being is better.

Final notes to this section: IFCO will be working to continue looking at the best way to address some of the comments and concerns coming forward. Themes listed above are a few that have been heard.

Website

Be encouraged! Learn more! Check out our website at: <https://individualizedfunding.ca/> If you haven’t been to the website lately and are not sure where to start, you might consider starting with a few of the tabs, titles or links listed below. Have some fun with it! Take your time as you learn more.

Say Yes, Ontario!

Many countries are seeing the benefits of various individualized funding models for people of all ages and challenges. From children through to senior citizens, people living with various developmental, physical, psycho-social, aging and memory issues have experienced the benefits of flexible, individualized models of support. We named this section on the website **Say Yes, Ontario!** because we are hoping that the Ontario government will ‘Say Yes’ in a big way to this type of support funding.

Here is the link to the Say Yes tab: <https://individualizedfunding.ca/say-yes/>

Look for these titles when you go to that page. They hold excellent information:

- **Individualized Funding – Did You Know?** (Note: This title poses a question to readers about whether they are aware of the success of individualized funding models in other places/countries.)
- **From Around the World - More International Research and Reports** (This title speaks for itself)
- **Made in Canada – Canadian produced publications, resources, and videos.** This section contains excellent resources from our own country. Our most recent posting under **Research, Reports, and More** is a paper written by Community Living Ontario called, *Building a Full Life + a Home of One’s Own in the Community*. This paper has some good ideas; it serves as a solid base for further discussion! Go to the site and read our summary of the document or link to the full document.

Resources

Check it out! Resources You Can Use!

Resources created by IFCO and/or partners include a variety of documents surrounding: citizenship, participation, and transformation; individualized funding; and independent facilitation and planning. Resources that support our work include documents related to our core values including the importance of supported decision making and individualized funding. We invite you to browse any of these resources through the various titles and links on this page. You can get to the **Resource** tab here: <https://individualizedfunding.ca/resources/>



Other Things to Think About

Some of you have been connected with the Individualized Funding Coalition for Ontario since its inception or since the symposium was held in 1998. That being said, you may be at a different stage in your life at this time. We wanted you to know about a few newer things on the horizon in Ontario that may interest you.

Seniors for Social Action Ontario (SSAO):

This is an excellent group of activists, researchers, policy writers and leaders from the disability world working with countless others who are concerned about the institutionalizing of seniors and people with disabilities in long term care institutions. They are working hard to get more flexible and individualized home and community care for Seniors, and to ensure younger people with a disability do not live in such institutions. They are sharing research about best practices around the world for supporting seniors in small homes in their neighbourhoods and communities. Check the SSAO website out: <https://www.seniorsactionontario.com/>. Sign up to be on their email list. You can also read the article that IFCO has written on the topic called, *Why Ontario doesn't need 'more' institutionalized supports for seniors and others living with disabilities*. This piece is being featured on the home page of the IFCO website. <https://individualizedfunding.ca/>

Microboards Ontario (MBO)

This is another newer provincial group/organization that is getting out good information on their website for individuals, families and others. If your family member or friend has had a support circle over the years, you may be interested in looking into the development of a Microboard as a next step. If you have an independent facilitator or another 3rd party/support person in your life who could assist your family member, you may consider talking with them along with your family member (son, daughter, sister or brother) about their interest. You may be familiar with the Bloomfield's story in Ontario, as they have presented at IFCO events and shared Andrew's story with IFCO members, families and allies in years past. See Andrew's story along with others on the MBO website at the link to Real Life Stories: <https://www.microboardsontario.com/real-life-stories.html>

People for Personalized Funding (PFPF)

People for Personalized Funding (PFPF), formerly the Special Services at Home/Passport Provincial Coalition, is an Ontario-based group of volunteer families and allies who support the use of SSAH, Passport, and other personalized funds to achieve an everyday life in community. Although it may look like a new group, they are the same organization with a new name. Their tag line says: *New Name. Same Commitment*. To learn more, go to: <https://www.pfpf.ca/about-us>

Looking Back

In 2014, the Select Committee on Developmental Services, an all-party committee, released its final report entitled: *Inclusion and Opportunity; A New Path for Developmental Services in Ontario*. Today many of the recommendations have not yet been implemented, despite the fact that all parties were represented on the committee.

Below are a few highlights from the report as published by IFCO in our July 2014 Message/News Brief. These points were important to our membership at the time. We thought you may want to take a look and if they still ring true, this gives you something to talk about with your MPP. Be sure to let your MPP know that there were representatives from each political party on the 'Select Committee'.

Highlights from the report of particular interest include recommendations that:

- would have the Ministry of Community and Social Services “support independent planning organizations whose role it is to guide individuals – with the help of their families, friends and support network – through key transition points so that the individual is supported throughout the course of his or her life” (page 9)
- would “ensure recipients of SSAH funding not lose that funding before Passport funding is in place and an individualized life plan has been completed with an independent planner” (page 10)
- state that “there be more flexibility in allowable use of Passport funding to meet individual needs” (page 10)
- state “the implementation of full direct funding options be fast-tracked” (page 10)

To view the Select Committee Report on Developmental Services, [Click here](#).

To view our submission to government: [IFCO Submission to the Select Committee – Jan. 2014](#)

Looking Forward

The Individualized Funding Coalition Leadership Group is working on actions/recommendations that were put forward earlier this summer by an Ad Hoc Working Group (made up of two leadership team members, and two partners/allies).

We are looking forward to continuing the work, along with friends and allies of the Individualized Funding Coalition for Ontario.

IFCO would like to contribute to and have an impact on future support in Ontario, with the hope this would lead to new ways of doing business. Stay tuned for more information on our website or in future news briefs.

