

## ATTENTION: Coffee and Conversations Participants and Registrants

### A Summary for You!

#### Hello families, allies and friends!

You are receiving this email and summary because you have participated in and/or showed interest by registering for a Coffee and Conversations Virtual Gathering with the Individualized Funding Coalition for Ontario (IFCO).



As you know, we recently hosted two virtual Coffee and Conversations gatherings. There was a great deal of interest in the events with over 40 folks who participated (people, families, and partners) and more than 50 who registered. We shared in some vibrant and timely conversations. Some of you were seasoned and experienced with individualized funding, others were there to learn more. Many thanks to those partners and allies who offered their support, added richness to the conversations, and who were able to respond to some of the questions posed by people and families who were present. Two documents have been attached with this email as discussed in the second gathering:

- *Have Your Say* event flyer, which is being hosted October, 4, 2021
- *Year in Review, April 2020 to March 2021, by the DSO, Central East Region*

Below are summary notes that include some themes, discussions and suggestions from the gatherings.

#### ***Historical Work and Relevance; Milestones and Definitions***

We learned together about some of the history and work that the Coalition has done since the mid 90's. This work has included: a symposium and work fest, learning events and community engagement; round table gatherings and collaborations; research, policy work and model design; papers, briefs and submissions. We learned that we can be assured that IFCO work and publications continue to be relevant, credible and timely for today. This can be seen by reading international research published in 2019 called: *Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review*. (See the link below.) At the second virtual gathering we also talked about some of the milestones and successes in Ontario with individualized funding over the years. And we shared some definitions of individualized funding that are recognized internationally. We will be putting that information into a document and sharing it later.

We agreed together there is a long way to go in Ontario to have individual voices heard, for people to have control of their funds and supports, and enough individualized funding to live an everyday, full life of their choosing in their neighbourhoods and community. We also talked about ideas and suggestions to overcome some of the barriers that were identified.

For those who were not able to attend and want to read more about individualized funding and all those 'features' IFCO has talked about over the years like self-determination, inclusion, community, citizenship, and social justice, check out our website: <https://individualizedfunding.ca/>.

To read about the research that we believe affirms the work of IFCO, see our co-chair's summary on the home page. Or read the actual report in article style format by the Campbell Collaboration at this link: <https://individualizedfunding.files.wordpress.com/2021/04/individualized-funding-interventions-to-improve-health-and-...-2019.pdf>

You can also go to the **SAY YES** tab on our website, and then choose the **Did You Know** tab for a short summary of the report and a **Plain Language** version of the research.

## **Discussions, Questions, Ideas, Themes**

Below are just some of the themes that families and allies shared with each other at our Coffee & Conversations gatherings.

**The \$5000 Passport Struggle:** The extreme difficulty that people and families are facing because of the \$5,000 Passport was expressed a number of times! What was being said:

- The small amount of support funding being provided as a standard amount doesn't reflect what my son/daughter needs.
- It does not provide enough funding to support someone to live a good life.
- One person noted that 2.5 hours a week is not anywhere near enough to be able to live ordinary everyday lives like most others in our neighbourhoods and communities.
- Families shared that trying to get additional Passport funding after accepting this 'measly' amount is impossible.
- A few families expressed their exhaustion, and their sadness for their son or daughter.
- In addition, one of our leaders with IFCO shared with our team that it has been more and more difficult to listen to people share their emotions as they wait for Passport Funding during these difficult times.

**Getting told there is NO "Individualized Funding".** It was reported by families that when people and families ask about larger amounts of individualized funding to support all aspects of life (community participation and support to live in a 'home of their own'), they have been told there is 'no such thing'. Some families have asked about individualized residential funding, and been told there is no process to get this. Other families also shared they have asked directly for individualized funding for all their supports through their DSO, but were told by the DSO, (and/or also agencies in their community) that it doesn't exist, with no way to ask for it. Families were wondering what to do.

At the gathering people and families were encouraged by others to reach out again to their DSO assessor, and make a formal request for individualized funding. They were encouraged: 1/ to ask that their request be added to their application, and consider using the term individualized residential funding; 2/ to follow up by email to put their request in writing; 3/ and, to ask that their request be clearly marked on their application, and sent back to them so they can see it has been documented.

We learned that some regions do have a place to check this off on the DSO application, Central East being one of them. For those that don't have a check box in their region, some families reported asked for it to be noted in writing somewhere on the application; this is so it could be reported on. We hope to gather information about what regions in the province are 'closing the door' to having individual funding requests added to applications. In the meantime, here are some of the suggestions that were shared:

- **Suggestions for what to do if you get told no:** If you have reached out to your DSO assessor with your request, and are told that it is not possible, or that individualized funding doesn't exist, you could ask to speak to the supervisor. You could also share the document called a *Year in Review, April 2020 to March 2021, by the DSO, Central East Region*. The document is attached with this email. It outlines the data the DSO Central East collects which includes how many individuals are requesting individualized residential funding in their region. It was suggested that this document could serve as proof that an individualized residential funding option can be requested at this time.
- **Consider some facilitation and planning directed by your family member:** If you haven't already done this: Ask your family member (son, daughter, sister or brother) if they would like to do some planning for next steps in their life. With the help of those who know your family member best, and if you have an independent facilitator or other 3<sup>rd</sup> party, you may want to take time to listen to the voice of your family member. When considering some planning with your family member and others, this could include the development of an individualized residential option - if that is desired.

### Other actions suggested by families, facilitators and allies:

WHAT TO DO WHEN LIFE CHANGES: As life changes, sometimes things get more difficult, and more support than first requested may be needed. Some people and families living with developmental disabilities are not aware that they can contact their DSO assessor and let them know what has changed, and ask that an update be added to their file (application and assessment). Even if you have a phone conversation, provide a follow-up email with your update to the DSO in writing, and be sure they have included it in your file. **Find an ally** in your community who would be willing, with your permission, to take your changing situation and/or an individualized funding/residential plan and budget forward. You could also let the supervisor of your DSO know what is happening and where things are at as well. **It was strongly suggested that you don't just do one thing and to take things beyond conversations to putting everything in writing with follow-up emails.**

BEING FORCED TO TAKE AWAY BASIC HUMAN RIGHTS. Families at both sessions talked about having to get a Power of Attorney for their family member because of the Family Managed Care Program Guidelines. For many, they say their family member is unable to give a power of attorney, so they are being faced with getting legal guardianship. This was expressed as a human rights issue having to strip their son, daughter, sister or brother of their rights as a citizen - to receive supports. With all of the knowledge about supported decision making and the UN Convention's stand on support for decisions by people with disabilities, this was expressed as a sad turn by families. Families have been told that if they don't get legal guardianship, then they cannot receive funding supports.

- At our second session a few suggestions were made. One partner spoke of some families in their area having success at getting a 'some sort of limited power of attorney' just for this one particular reason/need and it not extending to other parts of the person's life. IFCO needs to learn more about this before sharing more information.
- Also, at our second session, for those who are interested in how to 'possibly' find a way to prevent having to get legal guardianship, one of the leaders on the IFCO Leadership Team has a contact who may be of assistance. If you are interested in getting connected please email: [individualizedfundingcoalition@gmail.com](mailto:individualizedfundingcoalition@gmail.com). We will forward your request to our team member.

### Coming Soon: Have Your Say event!

**October 4, 2021, 1:30 pm**

The **Have Your Say** event has been designed for people who are using and/or are waiting for funding supports through developmental services. The event will be facilitated by Kory Earle. Kory is a member of the leadership team with IFCO. Please check out the attached flyer!



It has been especially difficult for people living with disabilities during the pandemic. This gathering is for people to share about their day-to-day supports and whether they have changed since the pandemic, and also to talk about what they need for a good quality life.

**Please share the flyer** with people you know, whether a family member, friend or someone you support who has a developmental disability and would like to 'have their say'. If you know someone who would need assistance to register or to get set-up for the event, please consider assisting with this.

**After the Have Your Say Event:** We know there are people with a developmental disability who have complex and unique ways of communicating. We also know there are others who don't do well in meetings. Because of this we are planning a follow-up opportunity in a different format for individuals who would need a different way to share their experiences and ideas.

If you know a person who would like to have their say, but wouldn't be able to participate in the meeting, please email us at: [individualizedfundingcoalition@gmail.com](mailto:individualizedfundingcoalition@gmail.com) . Please provide their name, email, and phone number of their contact person. Please state in the email that they would like to participate in the **AFTER the Have Your Say event** option. We will be in touch later.

### **Thank You!**

**Thank you for your interest in the Individualized Funding Coalition for Ontario.** Thank you for your commitment to people living with disabilities who would choose the option of directing their lives and supports. This means self-direction, control over funding and supports, relationships, involvement in their daily passions - with individualized funding as one of the mechanisms to make it happen!

IFCO will be hosting more gatherings for people, families and allies – stay tuned for those dates. In the meantime, **please help us promote the upcoming event for PEOPLE who have been labeled with a developmental disability by sharing the flyer attached with this email.** This way people will also have a chance to express their issues and their hopes for the future as well.

*IFCO Leadership Team*

*P.S. We will be sending out a Fall Newsletter to our data base soon, and are planning to include the Coffee and Conversation registrants. If you are NEW to IFCO and do NOT want to receive any other email communication from IFCO in the future, please let us know by return email, otherwise we will continue to keep you abreast of information. Again, thank you.*