

Individualized Funding Coalition for Ontario

April 2024 News Brief

‘THIS IS MY STORY’ Podcast Series

In our February 2024 News Brief, we introduced friends of the Individualized Funding Coalition for Ontario to our podcast series/stories project, with a promise of more information to follow. This project first got underway with its foundational and development phase in November thanks to a Family Engagement Grant from Community Living Ontario. Since that time additional funding was sought and secured through partners/agencies who believe in this work and the power of stories. This enabled our project coordinator, Judith McGill, and volunteer leaders including independent facilitators, to continue working on the second and third phases of this project. And to begin some conversations in order to move things toward a fourth phase of the project with the focus on a Northern Ontario component.



LAUNCHING THE PODCAST SERIES, TUESDAY, APRIL 16, 2024: Following this foundational work, we invited people, families, friends, allies, and professionals to an event on April 16th to launch our first podcast in the series, entitled *Reclaiming Adult Roles After the Pandemic*. We are excited about this first podcast for more than one reason. It launches the first of 5 or 6 stories that will be publicized as podcasts on-line and shared over the next year. The series will showcase stories told from many different perspectives. Although we originally shared that there would be 2 stories on this first podcast, with the rich information that was available for the podcast, a decision was made to highlight one story.

The ‘THIS IS MY STORY’ Podcast Series is good news for people and families. IFCO has been asked over and over again to share stories from people and families that have over the years secured and benefitted from two kinds of meaningful support. That is: enough/adequate individualized funding, as well as independent facilitation over time. We have been told that people and families want to understand how this kind of support contributes to building relationships and connections, and valued social roles as true citizens in their neighbourhoods, and broader communities. The ‘This is My Story’ podcast project has enabled us to fulfill the direction we received from people and families who participated in focused conversations with IFCO. We want to thank those who took their time to share candidly what they felt was critically important. This included: having people share what has been a significant contribution in their lives and what has worked in Ontario over the last 30 years!

PROTECTING THE PRIVACY OF PEOPLE AND FAMILIES: In moving forward with these stories, we are determined to maintain the privacy of the people and their families who are volunteering time to share about their lives – this includes their names and any other identifying information. This level of privacy is something families have said is critically important to them. We have discovered that people and families feel vulnerable about taking their story public. This has been holding them back from sharing their stories. Because of the times we are in, and the tightening up of ‘healthy’ and adequate individualized approaches and funding, there has been a great deal of fear among people and families who have had funding over the years. We are committed to honouring people’s privacy and anonymity.

PHASE ONE: With the Family Engagement Grant from Community Living Ontario (CLO), our project coordinator, Judith, completed the foundational work/phase one of the project. As shared in our previous news brief, this included the early development work, early conversations with people and families, and working with volunteer independent facilitators willing to be part of the project. It also included conversations and planning with IFCO leaders and John Klassen the Project Liaison for the CLO Family Engagement Projects. We want to thank John for his support and leadership, and also Community Living Ontario for the seed funding IFCO received to lay a strong foundation for this project – a new direction for IFCO.



THANK YOU to Community Living Ontario for the Family Engagement Grant that laid the foundation for our podcast project.

PHASES TWO & THREE: Funding from additional partners/sponsors made it possible for the 'THIS IS MY STORY' Podcast Series project work to continue seamlessly into phase two and three. This has included further preparation for the launch event with the person/family and the podcast, and developing the outline for hosting the event, and ability to hold other more localized events. It also made it possible to continue working with the independent facilitators and having conversations with people and families.

Both phases are being worked on simultaneously, and IFCO will continue to look for additional funds for what is needed to complete phase three. In the mean time we want to fully acknowledge and express our appreciation to the organizations that have provided funding for the majority of this project work.

THANK YOU to our valued partners/sponsors for their financial support of phase two and three of the stories podcast series:

Alice Saddy Association

Community Living Windsor

***Durham Association for Family Resources and Supports
(Durham Family Resources)***

Windsor-Essex Brokerage for Personal Supports

PHASE FOUR: Early conversations have begun with IFCO leaders and with our project coordinator Judith, around a northern component to our stories project. IFCO is aware that there are organizations and groups who have attempted over the years to have an individualized funding approaches in the north and also with a component for independent facilitation. We are grateful to those who have already been sharing their experience and knowledge with us. As the development work and conversations continue, IFCO leaders will also be working to increase our partnerships and to secure funding for this phase of the stories podcast project.

‘From My Heart to Yours’, Story Sharing Initiative in 2023

BACKGROUND: The Individualized Funding Coalition for Ontario (IFCO) made great headway with our ‘From My Heart to Yours’ stories sharing initiative last spring and summer. The work began in May 2023 with a story sharing event and continued with follow-ups and connections into July. Kory Earle, IFCO co-chair/volunteer leader co-facilitated the Story Sharing event with coordinator, Judith McGill. Volunteer story listeners were matched with story tellers to record the stories and help them finalize them later where possible. Topics included: the use of Passport funding, what their hopes were, what they understood about being able to direct their lives, and what their lives were like. All of the people/families/friends who came forward to share their stories had in one thing in common: they did not have adequate funding and/or support to live their lives like other every day citizens. As stories were completed, people received their own stories back to review and decide from there how they would like the stories used. In addition, the option of having them published by IFCO (anonymously or using their names) was part of the discussions.

In June of 2023 at the ‘Have Your Say’ event, some participants with the ‘From My Heart to Yours’ initiative shared their experiences. One person shared what it was like to be listened to and how much that built their confidence and belief in themselves, also thanking IFCO for holding events where people can feel safe. Story listeners shared what it was like to experience the honour of being trusted with another person’s story. Some of the volunteer story listeners expressed needing additional support and direction to assist the person/family in completing their stores. Some were being assisted by Judith.

The ‘From My Heart to Yours’ Story Sharing initiative in its first phase (which included preparing for gatherings and following up with people, families and story listeners), was made possible through in-kind support, volunteer leaders, and through IFCO membership funds. IFCO would like to thank the following whose support made it possible for the ‘From My Heart to Yours’ stories work in 2023.

Thank You! Your membership supported the ‘From My Heart to Yours’ Stories Sharing initiative in 2023!

- ***Community Living Welland Pelham***
- ***Community Living Windsor***
- ***Durham Family Resources***
- ***Inclusion Press***
- ***Windsor-Essex Brokerage***
- ***Individual members***



WHAT NEXT: Funding is needed to take the next step with the ‘From My Heart to Yours’ Stories Sharing work. In our last newsletter we spoke about having written funding proposals in the hopes of continuing our community engagement work. IFCO was not successful in securing additional funding for community engagement efforts at that time (aside from the small grant provided for the podcast project.) IFCO is committed to supporting those who want to and/or are now ready to publish their written stories. We also believe it is critical that IFCO share what we have learned from the people and families who participated in terms of common themes. Getting back to the next step with the ‘From My Heart to Yours’ Stories Sharing initiative will enable IFCO to continue this community engagement work. It is our hope that the IFCO membership drive for 2024 will bring in funds to support this work.

IFCO Membership Drive, 2024

The Individualized Funding Coalition for Ontario (IFCO) is putting out a call for memberships again this year. We would like to thank those who decided to become members in 2023. We are hoping that you might consider becoming a member again for 2024. For those who may be considering becoming a member for the first time, or the first time in a long while, we would invite you to go to the home page of the IFCO Website and scroll down to see what we have been doing over the last year and a half. Website: <https://individualizedfunding.ca/>



Considering Becoming a Member of IFCO?

For others still considering membership with IFCO, you may want to check out [*Now is the Time*](#), published in November of 2022. This paper outlines what people and families and allies have identified as important when implementing authentic and successful individualized funding approaches in Ontario. The information gathered from people, families, friends, independent facilitators, and agencies with 'experience', and from events, focus groups, research, virtual gatherings and more -- all comes together in this paper. For those who want to advocate for adequate individualized funding and other user-friendly support structures needed for success, getting familiar with [*Now is the Time*](#) is a good idea.

POWERPOINT: For a shorter read, you can check out the follow-up actions from the Now is the Time launch event by taking a look at the power point that was shared at the Have Your Say event in June 2023: [*Have Your Say, PPT June 13, 2023 FINAL*](#)

WHY BECOME A MEMBER: To learn more about why you may want to become a member go to the following link: <https://individualizedfunding.ca/membership-2/>

How to Become an IFCO Member

You can join the Individualized Funding Coalition for Ontario (IFCO) by using the link below. People, friends, families, professionals, autonomous networks, organizations and agencies are welcome to join. There is a place on the form to tick off your support of the IFCO Accord. Organizations and agency partners will be pleased to know that receipts will be sent directly to your email for your membership. Many thanks to Community Living Windsor, a long-time partner with IFCO, for setting up this safe on-line method for becoming a member! https://clw.formstack.com/forms/ifco_membership

BURSARIES: If you are a People First member, self-advocate, or family experiencing low income, OR a Family Network or People First Chapter with no operational funding, there is a link on the membership form you can click for a bursary to become a member. We welcome your memberships!

For anyone who would prefer to mail in their membership, you can do this by downloading and printing the: [*IFCO Information and Membership Brochure, 2024*](#)

- Fill out the membership form panel inside the brochure and mail it to: **Individualized Funding Coalition for Ontario, c/o 3357 Walker Rd, Suite 2, Windsor, ON N8W 5J7.**

Note: Supportive agencies and organizations who have supported some of IFCO's work with larger funding amounts receive an invoice, and they become members automatically. Invoices can also be provided to other agencies for their membership, as was our past practice, if requested.

OTHER NEWS

Upcoming Presentations and Outreach

April 25, 2024 - OASIS Conference

Kory Earle, co-chair of the Individualized Funding Coalition for Ontario will be part of a panel presentation at the OASIS conference in Windsor. This panel will be presenting the features of a 'new' paper developed by the Resources and Capabilities Committee, a part of the Inspired by Our Grassroots Initiative of Community Living Ontario. If you are at the OASIS conference, be sure and go over to say hello to Kory.

Leaders with the Individualized funding Coalition for Ontario have been volunteering their time, talent and experience in the development of the Resources and Capabilities Committee paper. Much of the work on the paper is rooted in the same values and principles found in the *Now is the Time* paper published by IFCO in 2022. The paper is called: ***Individualized Funding in Ontario, Possibilities and Pathways - Three Approaches to Work for All, Practical approaches leading to more opportunities and choices for people with support from families, trusted others, supportive agencies and organizations as part of a full life.*** The latest version, April 2024, will be available very soon for uploading to the IFCO website. Stay tuned!

April 27, 2024 – Family Engagement Forum, Community Living Ontario

Judith McGill, Kory Earle and Michelle Friesen will be presenting together about the Individualized Funding Coalition's *This is My Story* Podcast Series. The IFCO podcast project is one of five projects that will be presented at this Family Engagement Forum on April 27th.

THINGS TO DO

Stay tuned to the home page of our website . . .

Coming very soon! The link to the first podcast story in the series will be published on a streaming service and there will be a link to it up on our home page soon after the launch on April 16, 2024. This podcast is called: *'Reclaiming Adult Roles after the Pandemic'*.

We are committed to linking you to stories that demonstrate possibilities for people who want to live their life like other everyday citizens in their neighbourhoods and broader communities. This may be stories that are developed with the support of the 'coalition' and also stories created by others who hold similar values. Check back to the home page of the coalition's website from time to time.

RDSP advocacy made easier, see what Family Alliance Ontario has prepared . . .

We encourage you to go the last 3 pages of this Newsletter. **Attached is a letter from our partner, Family Alliance Ontario, encouraging families to advocate for changes to provincial legislation that will be critical to the future and people being able to withdraw their RDSP funds.** Following this information is a sample letter to send to your Member of Provincial Parliament. Note: Six other provinces/territories have already made changes and put things in place, (like supported-decision making practices), that will uphold the rights of people living with developmental/intellectual disabilities.



Picture from [Pixabay](#)

Volunteers, Supporters, Partners, Funders & Sponsors

*Much appreciation to the **60 different and unique VOLUNTEERS**
who gave of their time and talent to the
Individualized Funding Coalition for Ontario in 2023 and into 2024.
You have supported us in so many different capacities:*

Leadership group members - IFCO event facilitators and presenters
Story tellers - Story listeners - PowerPoint creators
Focused conversation groups - Outreach efforts
Conference presentations - Website and information updates
Committee work - Membership and invoicing systems
Project support, note taking, consulting, partnering and advising

*To our partners, funders, sponsors and members
THANK YOU for your valuable financial and in-kind support!*

Alice Saddy - Community Living Ontario
Community Living Welland Pelham - Community Living Windsor
Durham Association for Family Resources & Supports (Durham Family Resources)
Inclusion Press - Individual 'IFCO/Coalition' Members
Windsor-Essex Brokerage for Personal Supports

*IN-KIND SUPPORT: Family Alliance Ontario - Windsor-Essex Family Network
Ontario Independent Facilitation Network - Families for a Secure Future*

Individualized Funding Coalition for Ontario

To families who have a member with a disability Family Alliance Ontario is asking for your HELP!

In 2008, the Federal Government created a program to support Individuals to save for their old age - called the Registered Disability Savings Plan (RDSP) Although, this is a federal program, there are administration requirements of the Provincial Government of Ontario.

The Federal Government wants to make sure that there is proper support for people to open and draw from their RDSP accounts. The Federal Government is expecting Provinces to co-operate and bring in legislation around how people get supported to open an account and withdraw their funds.

Why should parents open an RDSP account you ask? Well once an RDSP is opened the federal government will put \$1,000 Bond into it each year until the individual reaches 49 years old.

Additionally, if a family member (or someone else) contributes \$1500 each year into the RDSP the federal government will add another \$3500 each year as a grant. People will be able use this money to help support the costs that increase as their individual who has a disability ages. Many provinces (6) have brought in legislation to ensure people have trusted support to manage and withdraw from their RDSP's.

The Province of Ontario has NOT yet brought in the legislation required. This means that in order for people to withdraw the money that has been saved on their behalf, they will be required to be declared incompetent and have all their rights as a citizen of Canada and their personhood taken away from them. This is NOT a good idea, or a solution to the issue and will cost the government a great deal of money. This is a terrible thing to have happen; as well it means a court case that can cost the individual a lot of money.

The alternative is that the Provincial Government of Ontario do what 6 Provinces have already done; which is bring in some legislation that permits trusted friends to support the individual to manage their RDSP funds. None of us make financial decisions alone. We might consult with other family members or with institutions who are set up to help us manage our finances. The belief that people with disabilities have to be declared incapable to manage their finances alone is really ludicrous. It is a violation of the Human Rights code as well as being contrary to Article 12 of the United Nations "Convention on the Rights of Persons with Disabilities" - to which Canada is a signatory.

SO, HERE IS THE HELP WE NEED FROM FAMILIES

Attached is a form letter that we are asking you to sign and send to your MPP (member of Provincial Parliament). We are hoping to get a provincial response to see if we can encourage the Provincial Government to enact the required legislation.

To find out the name of your local MPP and their office address please go to:

<https://www.ola.org/en/members/current>

Please send an email to your MPP and copy to: FAO (Family Alliance Ontario):

familyallianceont@gmail.com letting us know if you were able to send to your local MPP.

Thank you for your action. As families banding together, we are hopeful we can bring about the legislative changes that are required to benefit all our individuals with disabilities.

< Date >

Re: Urgent problems with Registered Disability Savings Plans in Ontario

Dear MPP < last name >,

I am writing you today as a family member and someone who cares about a person who has an intellectual/developmental disability. This letter brings to your attention an urgent issue that is creating a barrier for people with disabilities who require support to make decisions which jeopardizes their ability to open or access a Registered Disability Savings Plan (RDSP).

RDSPs were created by the federal government in 2008 to provide a mechanism for people with disabilities who are eligible for the Disability Tax Credit (DTC) to save towards their long-term financial security. People with disabilities, who would be seen as being unable to sign a contract, are prevented from being RDSP plan holders (they are unable to open or manage their own RDSP) therefore someone else must act as plan holder (a legal representative/guardian, a parent or biological sibling). People who do not have a guardian, parent or sibling cannot open an RDSP.

Although the issue of who can be the plan holder was identified in 2008, the Ontario government has been unable or unwilling to bring forth a model of supported decision making which would not require guardianship. Guardianship, which effectively removes a person's social ,economic rights and Civil rights, and gives them no say over who is in control of their life or finances, is NOT the answer. Placing people under guardianship is against the person's human rights; the Charter of Rights and Freedom as well as the UN Convention on the Rights of Persons with Disabilities. No one makes decisions in isolation but relies on those who care about them for help. Why should people with disabilities be any different; why should they lose their right to be involved in decision making. There is a better solution to this problem that has already been implemented in other provinces including British Columbia and more recently New Brunswick. This solution will safeguard people's investments, protect their rights, and reduce the burden on the Public Guardian and Trustee.

Over the years, the federal government has provided extensions to the provinces and territories to create a model that works and has expanded who can be the plan holder however, those extensions will be coming to an end in 2024. The result is that people with disabilities will be forced under guardianship to open or access their plan. In addition, many of those parents who are the plan holder for their son/ daughter are now in their seventies and eighties with no one legally able to take on that role. Many more people have not been able to open an RDSP because they have no family.

People with disabilities and their families and friends have financially contributed to these RDSPs as has the federal government through bonds and grants (which could be up to \$90,000). They are running out of time for a solution to be found however, we are asking this government to act now

We need your help to ensure that people with disabilities do not loose their citizenship rights by:

1. Work with people with disabilities, their families, and friends to develop a formula of supported decision making which does not impinge on people's human rights and protections under the Charter of Rights and Freedoms and is cost effective.
2. The capacity-related criteria used to grant or revoke the personal appointment of an RDSP legal representative should be based on the provisions of section 8(2) of the British Columbia *Representation Agreement Act*, which consists of several factors including the communication of a desire to have a representative, the expression of approval, and the existence of a relationship with the representative that is characterized by trust.
3. The relationship between the RDSP beneficiary and the legal representative would draw on protections offered through existing provincial legislation related to decision-making, e.g., the ability to appoint more than one legal representative, and requiring RDSP legal representatives to maintain accounts of transactions.
4. The RDSP legal representative would have authority to open and manage funds in an RDSP, including (in partnership with the beneficiary) consenting to contributions, deciding investments, applying for grants and bonds, and requesting that payments be made to the beneficiary.
5. The RDSP legal representative would have the duties of an attorney for property and be held to the same standard of care. These duties include encouraging an adult to participate in decisions, to the best of their abilities; consulting from time to time with an adult's family and friends; and making decisions in a manner that is consistent with an adult's personal care decisions. This standard of care would require RDSP legal representatives to exercise the degree of care, diligence and skill that a person of ordinary prudence would exercise in the conduct of their own affairs.

For further context, I am providing links to two recent documents that provide the stories of five Ontario families who are currently facing this serious and resolvable issue:

[Red Tape, Human Rights and RDSPs in Ontario – Part 1](#)

[Red Tape, Human Rights and RDSPs in Ontario – Part 2](#)

Sincerely,

< your name >

Cc. Betty Daley, President, Family Alliance Ontario betty.daley@hotmail.com
Doug Downey, Attorney General of Ontario Doug.Downey@ontario.ca
Brian Saunderson, Parliamentary Assistant to the Attorney General
Brian.Saunderson@ontario.ca

