

Submission to the Select Committee on Developmental Services

By the Individualized Funding Coalition for Ontario

Background

The Individualized Funding Coalition for Ontario (IFCO) has been in existence for 20 years with a membership that has consisted of people with disabilities, families, friends, independent facilitators, agency professionals and partners, and other provincial organizations. IFCO has been led by various volunteers who have lived experience with individualized funding and community inclusion through their various roles and positions – from people and families living with disabilities and independent facilitators to executive directors of direct-support agencies.

What We Believe – 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 a system of funding whereby the person requiring assistance, supported as appropriate by family and or significant others, has control over the funds allocated for his/her support. The basis for the work of IFCO and its existence lies in our accord as follows:

Our Work

Much of the work and direction for the Coalition's in the last few years has been primarily through the grassroots - volunteers who have come together to share their knowledge and wisdom. This includes: people with disabilities, family members and independent facilitators who have worked alongside direct -support agency partners and friends. Focus group gatherings, learning events, and more have been generously supported through the financial support of our valued partners, organizations, agencies and IFCO membership fees.

IFCO has a significant history of sharing information about individualized funding and the complimentary features needed in a system to enhance and enrich lives as citizens. We have done research, written documents, gathered people together for input, prepared policy papers, submitted briefs and educational documents and collaborated with like-minded groups committed to seeing individualized funding as a viable option for people living with disabilities.

Individualized funding is about having autonomy over an allocation of funds, controlling how those funds are spent to further one's life dreams, goals and plans. Individualized funding results in flexibility for the person who is: using the funds and making their own choices. The result, with the right complimentary supports can be a tailor -made life in community and full participation as a citizen.

Direct Funding – as it exists in Ontario for Special Services at Home (SSAH) funding and Passport - is one type of individualized funding. Individualized Residential Model (IRM) funding is another . . . and the list goes on. Not all individualized funding goes directly to the person and/or their family – nor is it all in small amounts. Individualized funding in larger amounts can be situated within the base budget of an agency, but remain protected and be tracked financially for the intended person. At the same time that person can have control over the decisions for those funds and their life choices.

It must be noted that IFCO supports the ideal of **supported decision-making** for people with disabilities. Trusted family and/or friends can support people to: make decisions, be listened to and direct their own lives, no matter the disability. We all need support at some point in our lives and we all have people we go to at times.

Decades Earlier . . . before Transformation

At inception 20 years ago, IFCO was aware that the use of individualized funding to assist someone to contribute and participate fully as a citizen (along with the support of facilitation and planning, financial accounting, and the contracting of support workers) was working in Ontario. By this we mean it was present in other ways besides just the use of SSAH. SSAH was the public face of individualized funding and a good way for young families to get the feel for what it was like to develop tailor-made supports that work for their families.

IFCO tracked the pockets of excellence over the years and the stories of success that existed under the old legislation in Ontario. Many individuals and families were encouraged and hopeful they would also be able to benefit from a similar model. All three political parties have been at the helm while people have utilized individualized funding in Ontario through the good will of agency partners, ministry offices and visionary leaders.

The experience and knowledge around how to do this successfully has existed for years among: agencies supporting the ideals, as well as people and families wanting to create something different. Accountability and tracking of not only the funding and how it was spent, but the quality of lives was always at the forefront of these situations.

IFCO members were more than willing to share their experience in the hopes they could influence the change that was being purposed by the Ministry of Community and Social Services at the beginning of transformation.

Many years later - after new legislation, pilot projects, and new features and programs – our members are claiming that the outcomes of this effort have been disappointing. It has not lead to more tailored and inclusive lives, directed by the person who has the disability, for those who would choose the option of individualized funding. In fact, our members have reported to us that the system has become more bureaucratic and significantly more rigid than what our experience was prior to Transformation and Bill 77.

ISSUES WITH THE CURRENT SYSTEM

We believe that there have been honest attempts to try and change the system by many committed people within the Ministry of Community and Social Services. We believe there have been good people involved. We also believe that somewhere along the way some things went very wrong and that it cannot all be attributed to a lack of resources since the downturn in the economy. There are a number of issues with the current system that IFCO believes are hindering people with disabilities to live their lives as fully participating citizens and causing hardship for families. They are outlined below.

Disproportionate Allocations of Individualized and Direct Funding

IFCO has kept track of the allocations to the Developmental Services budget over the years. We have noted that for those people and families living in their own homes who want direct funding (like SSAH and Passport) and those needing larger amounts of individualized funding to get on with their lives (like IRM) there has always been a disproportionate amount of funds being allocated to this large population group compared to others.

Today the percentage of the total developmental disabilities budget for direct funding stands at 8%. At present, 8% percent of the total budget is supporting close to 28,000 people and families with another documented 17,000 people waiting for Direct Funding (SSAH and Passport.) This does not take into account those who would like individualized residential type funding as this is not a statistic that has been captured. This percentage of funds going to people and families doing the work on their own has actually decreased in the last 8 years. It used to be 9.5% of the total budget. The consequences to this have resulted in the following for people and families:

- Thousands of people living with disabilities are without direct funding support for support workers.
- Thousands who have not had increases as their needs change – whether it be more medical concerns, getting older – both the individual and their parent.
- There have been no increases in support worker wages – unless choosing to go with less help. (Note: this has not been required for agency base funded supports – additional funds have been provided for wage increases and improvements to living arrangements and equipment over the last many years.)
- Crises are resulting because of not enough funding support when needed for people living in their own homes. Families are burning out and getting exhausted.

Recommendation:

Provide an allocation of at least \$300 M dollars for Direct Funding and Individualized Residential funding for children, adults and their families (and/or their trusted friends) who are willing to do most of the work themselves. . . . To make it right.

Cutting Teenagers off their SSAH at 18 years of age

One of the very unfortunate policy decisions made by the current government was to cut teens off their SSAH when they turn 18. This has caused a great deal of anxiety and stress for families. Given the pressures facing families as caregivers, honouring and respecting their contribution of 18 years is important. As such our recommendations follow.

Recommendation:

1/ Allocate an adequate amount of additional funds to the SSAH funding envelope to support children with disabilities and their families in Ontario (as stated above) and abolish the practice of cutting people off at 18 years of age.

2/ At the age of 17, ask children with developmental disabilities and their families to submit their documentation to prove eligibility (meeting the requirements of legislation) and once confirmed they would continue to receive their direct funding. This would reduce lots of anxiety and stress. At whatever time they feel more funding is needed – than they could proceed with the formal, rigorous process to apply and be assessed within the adult system through the DSO. (See comments about the DSO later in document.)

Developmental Services Ontario – Rethink the Model Design

Previous submissions to government around transformation have included the IFCO position on 'separation of functions'. Persons with disabilities need the option of receiving supports and services without conflicts of interest. Some of our priorities have been: that facilitation and planning needs to be separate from the direct service system in order to avoid conflicts. Decisions about who gets resources should not rest with the person who is assisting someone with an application – whether new allocations or matching or existing, etc.

The DSO has been created with too many functions under one roof and has been given too much power in the system – system navigation, assessment, crisis intake, information, matching of resources, etc. In addition to this issue, the Supports Intensity Scale assessment as a practice is not providing anything value added to the lives of people and families. Reports to IFCO from across the province speak to how difficult this process is. Some talk about how hurtful. Others are appalled. Many say it is a waste of time. The stories are heart breaking. We believe there are other more respectful ways to determine what people need and what budget they would require to be supported.

The model design for the DSO is flawed. The intention of having a fair process so that those most in need of supports will receive them is not being realized. At present those who receive supports by being matched to a resource/spot in the system are often far down on the waiting list as agencies and the DSO's negotiate who should be supported. For those who want an individualized funding option or support - there are no choices. The system is not responsive or flexible.

Recommendation:

Abolish the DSO in its present design. Replace the SIS assessment process with something more respectful. Recognize that when thousands of people are waiting for support – 100's will have the same need no matter what system is used to assess.

Independent Facilitation and Planning needs to be a Viable Option

Independent Facilitation and Planning is an effective support for people with developmental disabilities who want to develop relationships and live a tailor-made life in community as a participating citizen. It offers: deep listening, information provision, bringing people together in support networks, facilitation, planning, mediation and negotiation – whatever the person needs. Independent facilitators assist the person with trying new things and with standing beside them over time as they get stronger and more involved as a citizen. Independent facilitation is a function that compliments and supports people who use Individualized Funding – assisting them and their trusted family and friends to do the work.

Recommendation:

Base fund independent facilitation and planning in order for it to be a viable option for those who would choose it. This would ensure it is available to all - no matter what background or economic or cultural reality a person is living. Operating independently of direct-service providing agencies to ensure autonomy and independence is key.

Summary: IFCO Priorities

It was important that IFCO share the things that we believe need to change in order that more individualized and tailor made options can exist for those who would choose this. We understand that the traditional system is loved and wanted by many. We also believe however that it should not be imposed on everyone. We would like to see individualized funding as a viable option –providing adequate, portable and flexible funding to people.

Key Feature: Choice and control

The most important feature identified by people with disabilities and their families using individualized funding is having control and autonomy over their funds and their day to day life and decisions. This desire for control and choice while creating a meaningful life as a valued citizen also results in safeguarding vulnerability due to the relationships, presence, participation and contribution in community.

IFCO strongly recommends the following priorities:

- **Decision-making** that rests primarily with people with disabilities along with the support of their families, friends and others – those they trust (supported decision making).
- **Looking to Community** and all the resources we find in community as a first resort for building a good life.
- **Independent Facilitation and Planning** that is based funded in Ontario as a viable option.
- Adequate funds for disability supports that are **individualized and portable** - coming from government, either from existing base budgets that are unbundled or new funds.
- **Respectful processes for applying for supports**, keeping functions separate to avoid conflicts and placing too much control in one place.

Respectfully submitted by:

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