

Individualized Funding Coalition for Ontario

Feedback on the Changes to the Passport Program

November 5, 2012

Introductory Comments

The Individualized Funding Coalition for Ontario has an 18 year 'track record' of contribution, partnership and community engagement. Throughout our history, we have done our work under an 'Accord' that outlines what we believe, as follows:

"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 access to and control over the funds allocated for his/her supports."

Our earliest partnership with the Ministry of Community and Social Services (MCSS) began in the 90's. We participated with MCSS and others on a Symposium about Individualized Funding which was held in Orillia in the late 90's. Speakers attended from all over the country. Ontario's experience at the time was primarily around the success of Special Services at Home as a direct funding program. As well there were small pockets of success where agencies were supporting people by keeping their individualized funding budgets separate. From that was the learning about the type of support that people and their families needed in order to manage and direct their funding. One of the presentations at the event referred to this support as the building blocks of individualized funding.

Over the years experiences with individualized funding and those building blocks increased. Evaluations of specific projects were positive. Best practices were being tried and tested. Stories were being shared. By the year 2001, IFCO was coordinating various community engagement events in different cities around the province where: stories of full citizenship were shared; involvement in one's community with the support of individualized and/or direct funding and independent facilitation was explained. By 2004 a large Workfest was held where more than 120 people, families, facilitators and agency partners gathered to develop a work plan for the future.

When IFCO had the opportunity to get involved in the Transformation efforts in Ontario, we were more than pleased to commit our time and energy. We had great hopes that people with

developmental disabilities would experience more freedom and support to live everyday lives like the rest of us.

The introduction of the Passport Program by MCSS in the year 2005/06 as a complement to the Special Services at Home (SSAH) program was seen by our membership as a positive beginning. As stated in the SSAH guidelines: "*Passport and SSAH are complementary in both aim to support an individual's personal growth and independence in the community' and 'the Passport initiative is in addition to SSAH"*. We supported this direction whole heartedly. SSAH proved to be helpful in supporting people as they entered the adult system at a stage of their life when applying for additional funding was so critical. Passport was a great next step. The introduction of the Innovative/ Individualized Residential Model Initiative funding in 2007 was received enthusiastically by our membership.

Much has transpired since those more hopeful times of Transformation. Despite the setbacks that have occurred, the Individualized Funding Coalition for Ontario (IFCO) appreciates the opportunity to provide feedback to the Ministry of Community and Social Services on the Changes to the Passport Program. However, we do not believe we can effectively provide feedback about the Passport program without providing feedback about SSAH as well.

The Individualized Funding Coalition for Ontario does not support the decision by MCSS to make Special Services at Home a children's program only. The importance of young adults having seamless transition into the adult system and remain able to continue to receive direct funding at the age of 18 has been brought forward at the Partnership Table by various members on numerous occasions over a two year period. The importance of people with developmental disabilities having supports they can count on into adulthood has been made clear. We believe cutting off direct support funding to teenagers turning 18 as of April 1, 2013 is a decision that can and must be reversed. As such we are providing feedback that figures SSAH into the equation and lays out a process for this to occur.

IFCO cannot provide feedback on the Changes to the Passport Program in isolation - without commenting on SSAH. In addition several references are made in the slide deck about concerns in the 2011 Auditor General's Report. As such IFCO would also like to comment on some of the concerns and facts raised in the Auditor General's Report.

IFCO Overview

The Ministry is quoted in the Overall Ministry Response in the 2011 Annual Report of the Office of the Auditor General of Ontario as follows: "*We are moving to a single direct funding program to make the system easier to navigate and more flexible for individuals and families.*" IFCO would note a few things with regard to this statement:

1/ The Auditor General did not put forward recommendations about the need for making the system easier to navigate with regard to SSAH and Passport, nor was there any recommendation for it to be more flexible.

2/ Prior to the changes individuals and families found it easy to navigate the SSAH system and appreciated being able to continue those supports into adulthood.

3/ our membership and other grassroots groups are reporting that the changes being made to SSAH are making the system more difficult to navigate for individuals and families. Individuals and families across the province indicate that having their SSAH funding cut-off and re-applying to Passport has caused a great deal of concern and distrust.

4/ Further into this document, IFCO will propose a transition for individuals turning 18 and their families that is easier to navigate and offers more flexibility.

Strategy to manage SSAH wait lists

The 2011 Auditor General's Report refers to the decision made by MCSS to freeze SSAH funding in the 2008/09 fiscal year "while it looked at ways to address the gap between the growing demand and available funding." Reference is also made to the growing wait list in the Report. MCSS has chosen to address the growing wait list for children by cutting adults off their SSAH and giving said funding to children. The strategy is flawed in terms of how responsive it can be for children with disabilities in the short term while at the same time puts young adults and their families into crisis.

Clarifying eligible expenses for Passport

The concerns raised by the Auditor General about Passport and SSAH regarding the need for clarification of eligible expenses, make sense. We appreciate the efforts of MCSS to look at this and ensure clear direction for individuals and families. However, we are concerned that as part of that effort some legitimate expenditures will be eliminated.

Sufficiently detailed invoices; modernizing accountability

According to the Auditor General, *"the Ministry and agencies that administer SSAH funding should obtain sufficiently detailed invoices, and where applicable receipts - to ensure that the amounts claimed are in fact eligible and reasonable before funds are dispersed."* According to the MCSS slide deck regarding the Passport Program, one of the key changes is about Modernizing Accountability. Individuals and families will submit quarterly reports to the *"Passport Agency for review, approval and/or reimbursement. They will retain all invoices and receipts for a period of time."* In the old system invoices were signed and went in regularly. Sending in a quarterly report could be additional work for families and a cause of more stress. More understanding of how this will meet the standards set out by the Auditor General and also how it will be easier for families is needed.

Change of emphasis applauded

MCSS has stated that *"respite supports should be used to enable an individual with a developmental disability to have personal goals and positive outcomes while giving the primary caregiver a break . . ."* We also know that Community Participation Supports through Passport Funds also ultimately result in a break for individuals and families. IFCO supports the emphasis on the individual being supported with direct funding to have a good life.

Teenagers with a developmental disability moving into adulthood:

It is critical to address the fact that teenagers with a developmental disability do not "age out" of the need for SSAH (direct funding) at age 18. As such they should not be cut off this funding when they reach 18 but rather continue receiving those supports 'if eligible'. IFCO proposes that a process be designed with the aim of supporting young adults to enter the adult system in a simplified way, confirming their eligibility in advance and keeping their SSAH funds intact.

Suggested Process for 18 year olds entering the adult system

Recognizes that developmental disability is life long, therefore people need to be supported through the life stages with no breaks in direct funding for their support workers.

Rationale:

- Recognition that individuals have already been assessed and allocated funding for the journey through the SSAH program as a teenager
- Ensures consistency of support to prevent families from falling into crisis, to enable people to keep the support workers who they have a relationship with, and minimize upheaval and stress.
- It honours and respects the reality of how difficult transitions are.
- Respects that as people get older they often need more support and it becomes necessary to build on existing supports as life changes.

Under the newly transformed system of support for Developmental Services: **People and families will continue to receive their SSAH as adults under a new name: Passport Respite.**

Steps you can expect as a family:

- Two years before their 18th birthday people will receive a letter about how to confirm their eligibility for Adult Developmental Services. It is assumed under the new transition protocols that most people will have already been made aware through their school boards. However, this will ensure that no one falls through the cracks.
- People receive a deadline for submitting their paper work for determining eligibility.
- Once eligibility is confirmed, they receive notification of the administrative changes related to the new program (Passport Respite) including information on admissible expenditures.
- People and families will make decisions about where to put their funding once they are 18 as per Ministry time-lines provided.
- Also provided in their letter will be information on the DSO application process and how to apply for any other adult services and supports.

Benefits: This is a very cost effective approach for the government for youth making the transition to the adult system. Youth turning 18 continue to receive their Direct Funding in a seamless manner. If they are interested in any supports over and above this funding they would then enter the Assessment process laid out by the Legislation and implemented by the DSO's.

Additional Issues Identified

- Adults who were on the SSAH wait list for ADDITIONAL SSAH funding do not have a way to receive that funding through the transition to Passport. There is no process outlined in the Passport slide deck to respond to that.
- Students between the age of 18 and 21 need a process to apply for Passport Funding while they are in school. We see no indication of how that could happen in the 'Passport slide deck'.
- References to "overlap" or "duplication" in the Passport Slide deck are misleading. SSAH and Passport funding have always been complementary (as stated in the SSAH guidelines " both aim to support an individual's personal growth and independence in the community" and "the Passport initiative is in addition to SSAH") as people with developmental disabilities get older and need more support to have a life. The Ministry should reword the Passport Guidelines to remove any inference about duplication or overlap. A process could be outlined in writing that would demonstrate to individuals and their families – both in principle and in action - that both types of funding are available, attainable and highly valued as complementary funding sources on the journey.
- No one should lose funding from either source of direct funding because of any perceived overlaps as they go through their Application and Assessment process. In addition, people who do not have SSAH or Passport Funding need the opportunity to apply and receive SSAH-type funding (now called Passport Respite funding) and also Passport Community Participation Funding without penalty and/or processes designed to exclude or reduce. Families work very hard to use their son or daughter's SSAH in creative ways for personal development and community participation. This means that the individual can participate in community life and at the same time get a break from their families, who also get a break. Adults and their family caregivers need both sets of funding and more . . . much of the time.
- Common Vision members at the Partnership Table have repeatedly requested that the Ministry expand Direct Funding so that it takes into consideration the need for residential supports - similar to the IRMI initiatives that were short lived. There is no evidence in the Passport slide deck that MCSS is headed in that direction. We are told that Passport will be the only venue for Direct Funding in the future. Individuals and families are concerned that the system is being created to support those people who can manage on limited funding like Passport. This has a discriminatory impact.
- Many who have participated in the Application process and SIS Assessment have found it difficult to imagine an expanded Direct Funding program. They are offered particular choices in the application that do not fit with the direct funding approach they envisioned. It is very different from what individuals, families, family networks and provincial coalitions have talked about since the beginning of Transformation in 2004.
- The Passport slides outline going through the Passport Decision Guide once eligibility is determined through the application to DSO - then being sent to a Passport Designated Agency

who completes the Passport Decision Guide to determine level of funding. There is no mention of a SIS Assessment.

- It is also not clear what would happen if an individual just wanted Passport Community Participation funds and nothing else. Could an individual do the application process and then receive an allocation or prospective allocation of Passport Funding before the SIS was completed? Does the Passport Decision Support Guide provide a Standardized process to determine funding amount that would be acceptable in legislation OR is the Ministry anticipating individuals will need a SIS Assessment and a Passport Decision Support Guide assessment to receive direct funding?

Critical to Successful Community Involvement: Expenses for Passport Funding

IFCO understands that MCSS is proposing that Passport funding not be used to cover expenses other than the hiring a support worker. Not being able to use funding for participation costs will severely limit participation in the community because individuals will have support workers and not be able to afford to do anything in the community with them. We believe this is not the intention of the program. Most families are already contributing considerable out of pocket dollars on disability related expenses to ensure that their family member is well supported. Many families' have chosen to purchase and fund homes for their children to live in and pay for additional support workers to provide in-home support. The current income from ODSP is well below the poverty line. Individuals with developmental disabilities have minimal levels of discretionary income to spend on a monthly basis. Without the possibility of using Passport dollars for community participation individuals will be far less able to participate in the community.

Exceptions in spending:

IFCO is pleased to see there will be some exceptions in spending. Two of a few things that need consideration are: Indirect support and the hiring of family. Would the Ministry consider a maximum amount for indirect support so that there is a small amount of flexible funding in everyone's life? What if families are between workers and a family member could be hired for a time while they find someone? Could there be some time limited parameters created for such situations?

The relationship between direct funding and independent facilitation and planning

IFCO believes that individuals and their families or significant others who use direct funding need the support of an independent facilitator. An independent facilitator assists the individual and family to build capacity and strength. Often support is needed for human resource roles, team meetings and more. Taking risks and trying things works best when there is encouragement from a third party. In addition the facilitator would play a role in the community connections and building relationships.

Summary

IFCO would welcome an opportunity to speak with MCSS on the subject areas addressed in this submission. We thank you and look forward to hearing back from the Ministry.