

Fall News Brief 2013

Respectfully Taking Pause

Before beginning our fall update and review, we would be remiss if we did not pause to reflect on the historic times we are in. On Tuesday, September 17, 2013 an out-of-court settlement for \$35 million, which included an apology, for the people who lived at Huronia Regional Centre was announced. (See the attachment provided with links to various media coverage.) How does one begin to thank the many courageous people who came forward to share their stories of horrific abuse and humiliation as part of the recent class-action lawsuit? This is especially true of Marie Slark and Patricia Seth, who were willing to stand strong, front and centre, with the support of Marilyn and Jim Dolmage. The settlement, which still needs court approval, includes a commitment to maintain the cemetery at Huronia and create a registry of people buried there - so that no one will be forgotten. As a mother who, like many of my friends and colleagues, has focused efforts for the last 32 years on my daughter being able to experience a life of value and worth amidst family, friends and community there are no words to describe the feelings that arise. Sincerely and respectfully - *Michelle Friesen*



Our Fall Update and Review

Our last regular IFCO meeting was held in April. Since that time IFCO members and leaders have been involved in the following:

- Continued lobbying and education for adequate allocations of individualized/direct funding.
(Just a reminder of our rationale for this continued effort: individualized or direct funding for Passport, SSAH or individualized residential has been considerably underfunded in comparison to traditional services. Many people along with their families/friends have indicated they would like a life that is tailor-made participating and contributing in their communities.)
- Continued lobbying and education regarding the value and importance of independent facilitation that is base funded (in conjunction with opportunities for individualized funding in larger amounts than Passport for a whole life in community.)
- Contacting the Ombudsman's office.
- Participation at the Ontario Independent Facilitation Network (OIFN) Forum May 10th and contributions of time to OIFN activities/subcommittees.
- Participation in local and regional independent facilitation networks and initiatives.
- Participation on local Transition Protocol Committees. *(This involves three Ministries: Education, Children and Youth and Community and Social Services.)*
- Partnership Table involvement.
- Leadership group video and/or teleconference meetings with MCSS and others.



A great deal of time went into receiving feedback, getting contributions, writing and putting forward ideas by IFCO members to a variety of documents/initiatives/writings last fall (2012) and through the winter (2013) – not to mention the two years prior to this following Ad Hoc meetings. As such these last few months have been quieter with regard to document work. However, other areas were busy. We again would like to thank all our members who have been doing advocacy and educational work in their own communities and with their MPPs.



Advocacy, Activism and Education: Making a Difference

Funding Announcement

Soon after the \$42.5 million for Developmental Services was first announced I received a phone call from a colleague and friend in Windsor who said, “I know that this is not near enough and not entirely what has been advocated for, however, I think the activism has had some success.” She really wanted me to believe that. She knew that efforts by Family Networks, IFCO members, and others - individually and collectively - had been about expressing that it was time to support people and families by investing in individualized/direct funding - **it was just time**. Such supports had historically been highly underfunded given the numbers of people being supported outside the traditional systems – mostly by their families. Yet, my friend wanted me to consider the idea that the advocacy efforts did pay off because very few other things received increases. I took her at her word and appreciated the positive feedback. But it does not mean we stop; we need to continue advocating for more individualized and direct funding.

In the advocacy and education work many of us did, dollar figures from the Everyday Ordinary Lives Ad Hoc group were used – which were much higher than the total announcement. In the end approximately one quarter of these new funds (\$42.5 M) are being made available for Passport Funding for adults with developmental disabilities.

Actions: We would encourage all IFCO members to continue to educate others about the merits of adequate direct and/or individualized funding for those who would choose this option. Find examples/stories to demonstrate how much of a difference the development of an individualized tailor-made life really makes:

examples of contribution in community, connections with family and friends, support from personal assistants/support workers who facilitate real participation, and the flexibility of individualized funding around the ups and downs of life. For those who have experienced it, you can share the value of independent facilitation for walking with over time and strengthening relationships and networks. Use statistics that demonstrate the very small percentage of the developmental services budget that is going into individualized and direct funding compared to other services.



Changes to Passport

By now you have heard about the changes announced to Passport Funding. The main changes include being available to 18 year olds in school, those on ODSP Employment Supports and being able to use it for care-giver respite. In addition, you may have heard about the restrictions around not using the funds for what the Ministry calls “indirect respite”. In the past people with SSAH could use the funds for assistance with cleaning, lawn cutting, etc. if they needed family to support them. Only in exceptional circumstances and only after approval from the Passport agency will this be approved. Other recommendations that came forward to MCSS will be considered later. IFCO had put forward concerns about the lack of flexibility with the funding and along with others advocated for same. As such it looks like the exceptional circumstances is where things have landed. Some are suggesting that this will make things difficult for those who have sons and daughters with medical needs as an example who cannot find support people who can perform certain tasks. It will be important that scenarios requiring exceptional arrangements are accommodated and we all need to keep our ears to the ground on this.

Larger Amounts of Individualized Funding – for a Whole Life

The IFCO leadership team takes every opportunity to share the importance of larger amounts of individualized and/or direct funding are for those who want a life in their community designed and developed outside the traditional congregate supports. We also share how those who are ‘outside the traditional supports’ can benefit from the option of independent facilitation – from relationship building to having someone stand with them over time through the planning, trial and error, risk taking, tough discussions and decisions. We believe support needs to go beyond ‘Passport’ or talk of ‘respite’ and continue to express that to the government.

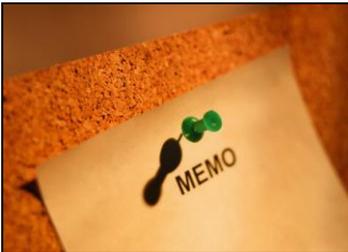


We have had feedback from families who have been told by various professionals that there will never be larger amounts of individualized funding available and/or increases for those who already have individualized funding beyond Passport. That has been puzzling because it was our understanding from the Partnership Table over time that the Ministry of Community and Social Services (MCSS) would be moving to a model that includes the option of having allocations of larger amounts of individualized funding. For those of you who have heard such things please know that at the latest Partnership Table meeting, held on Sept. 12, 2013, it was confirmed that the Ministry is continuing to look at the option of larger sums of direct funding. They may be moving slowly and they may not have everything figured out - but their intention is to have that option available in the future. Some Partnership Table members expressed their concern at how long things are taking. The Ministry acknowledges that there is not enough funding currently – but the intention to have the individualized approach remains.

Many IFCO members have commented about the discouragement around a matching system that looks at vacancies as a resource. Some people waiting for supports are not interested in a vacancy – and would rather create their own living arrangement with individualized funds. This has made it difficult around matching when someone who is deemed most in need does not want the ‘spot’. As such the system is not necessarily supporting those who are most in need – but

rather the person who best matches the resource available – and that person could be a long way down the list. In the end it appears that the Ministry is working on how there can be flexibility built into the current approaches. IFCO will continue to follow this progress as will other grassroots groups at the Partnership Table. **The most important thing to take away from this is that there is still a plan to have additional individualized funding available to people beyond the maximum of Passport into the future.** Next time you hear that there will never be additional allocations of funding that is individualized – you can be assured that this is misinformation and not the official word from MCSS.

Actions: Encourage people and their families, who are going through the DSO process and who want individualized funds, to ask that the choice of Individualized Residential Funding be checked off on their form. They can also state that they would like all of their funding supports individualized by having it noted under OTHER. Many people have shared that they are not told about these options while going through the application and assessment process. We need to get the word out for people to ask for it and to ensure it is done.



Independent Facilitation and Planning

The Individualized Funding Coalition for Ontario (IFCO) continues to provide information, data, experiences, stats and stories regarding independent facilitation through member organizations and individuals with lived experience to the Ministry of Community and Social Services. We also have members actively engaged and supporting the Ontario Independent Facilitation Network as volunteers and working each other from community to community across the province.

The Individualized Funding Coalition for Ontario and its members – agencies, families and individuals - were first to express the importance of independent/individualized facilitation and planning to support a full life in community and also as a complimentary support to having individualized funding. It is wonderful to continue those partnerships with each other as we continue to faithfully advocate and educate about the importance of this feature in Ontario's system of developmental services. It is also wonderful to be partnering with the Ontario Independent Facilitation Network which creates opportunities to share and for people to connect from across the province.

In the spirit of sharing information, we have attached a booklet prepared by Windsor Essex Brokerage for Personal Supports over the summer that outlines their journey with independent facilitation which started in 1997. It contains a bit of history, current stories and also maps out in chronological order the evaluations, reviews and studies that they have been involved in over the years. Brokerage, like others, has always been willing to share what they have experienced and learned selflessly throughout the province. Many of our members have been beneficiaries of the volunteer time this organization has offered.

Ombudsman's Investigation

Well over 800 complaints regarding developmental services have been put forward to the Ombudsman's office since the announcement of the investigation into Developmental Services in November 2012. The investigation team has conducted over 190 interviews. According to their Annual Report 2012-2013, the interview and evidence gathering phase is almost complete. However, in a call made to the office this week, we learned that new individual complaints are still being reviewed with no time-lines yet on when the cut-off will be. The investigation team is assessing the evidence. The Ombudsman expects to report later this year. If you have not called and feel you have an important story to tell please consider connecting. In particular, if you know a family who has been cut-off their SSAH because they turned 18 – who have seen life put into a tailspin – then please encourage them to call 1-800-263-1830.

Special Services at Home Funding: Let's not forget the children

We need to be ever mindful that the first form of individualized funding in Ontario was Special Services at Home. We need to understand its birth, its history, its relevance and value in the evolving history of supports to people with disabilities and their families. SSAH was one of the government's answers to keeping people with disabilities at home and in their communities. It is through SSAH that we learned of the value of an individualized tailor-made support and how larger amounts of funding are needed as things get more complex, people get older and/or more independence is needed. It was how we learned about respect for the life continuum into adulthood for those with developmental disabilities. We need to continue to advocate as an IFCO for the children who turn 18 and then lose their support funding – it is a huge assault on these teens and their families. It is a devaluing of their lives – a devaluing again of people with developmental disabilities. We need to advocate that adequate NEW SSAH funding be a priority for this government for younger children as well. 'They' have not fixed the problem. As 'they' cut teens off and pour funding back into SSAH each year, more and more children will be diagnosed with disabilities. Huge waiting lists will still abound! Thousands continue to be without support today.

I cannot help thinking about the recent settlement for those who lived at the Huronia Regional Centre in this regard. So much of this class action suit is about validating and valuing stories and heartache, not ignoring, and not forgetting. It is ironic that at the same time the government starts to make it right by acknowledging those so harshly devalued in the past – they are not valuing those living with developmental disability in the present, particularly those people who are living at home with family or want to live on their own with the support of family and friends. This includes:

children, teens, adults and their family supporters: parents, sisters and brothers, grandparents.

Will continued advocacy, activism, and education make a difference? We don't know for sure – but we know that we cannot stay silent.



Partnership Table Activity

Ending the Wait - An Action Agenda to Address the Housing Crisis Confronting Adults with Developmental Disabilities

I have attached the Initial Report by the Housing Study Group (Developmental Services Sector-Ministry of Community and Social Services Partnership Table) for your reference. A number of members at the Partnership Table have been meeting over the last year to take a look at the current situation with regard to housing. Ron Pruessen, a parent from the group *Opportunities Mississauga for 21+*, initiated the idea and has been a committed leader in their work.

Please note that at the back of the document on page 21 you will see a Survey that was used to gather information. At the time the survey came out it was first thought to be for group living arrangements. We have since learned that the Survey could be used for information about **individual** innovative arrangements and that surveys can still be put forward as there is an expectation of ongoing work over time. This may mean using the OTHER category under some of the survey questions.

Individuals (and families) who have worked on an Individualized Residential Model proposal who would like information submitted to help inform the work and future direction could put the Survey forward (without using your names.) A contact person from a trusted organization could be used to keep your individual names confidential. It is more about what it is that people are planning and/or doing. Organizations who have assisted people and families with Individualized Residential proposals could connect with individuals and ask them if they would like to participate – and perhaps facilitate the process. This additional information would broaden the scope as the Housing Group enters its next phase. Ron Pruessen, who has been leading the work, sees this as an ongoing process and was supportive of the idea of more information coming forward.



Actions: Please forward your survey responses to desk5@webps.ca where surveys will be received on behalf of IFCO. They will later be forwarded to the committee for the next phase of work.

Additionally if you are part of any local initiatives about creating affordable housing arrangements/homes in partnership with other community endeavours that could be considered for people with developmental disabilities - that are individualized and tailor-made - the Individualized Funding Coalition would be interested in hearing about them. For example: some municipalities may be working with individuals, families or groups around their Ontario Renovates initiatives or Affordable Housing Strategies.

Individualized Funding, Independent Facilitation, Relationships and Community! Moving Forward!

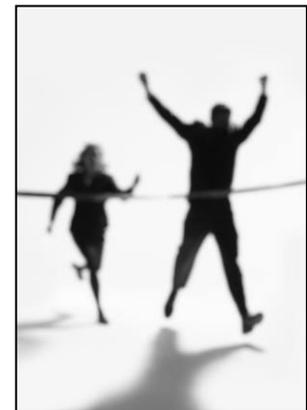
Things we have learned: activism can be life-long and change takes a very long time. Many other human rights and social justice movements have born this truth out.

The year 2014 will mark the 20th anniversary of the Individualized Funding Coalition for Ontario. How we mark that is something we have not yet spoken of as a group. We hope to begin some conversations around this at our next meeting. **The point being – the Individualized Funding Coalition for Ontario has been at this ‘change’ work for 20 years!**

As we look ahead to the balance of this fiscal year there are a few things that the Individualized Funding Coalition for Ontario has in the ‘hopper’. The dilemma: going forward with the creation and completion of resources and information and/or identifying and executing the next phase of education, advocacy and learning for the government and others or both. There is a great deal of valuable information that has been gathered from people, families and facilitators at Ad Hoc meetings regarding lives using individualized funding and independent facilitation that is powerful and yet to be published. We have also done some preliminary writing and work about independent facilitation with our members and partnering organizations that is waiting for further refinement and completion to publication stage. And we are looking at reinvigorating and updating the website and other social media – again.

At the same time current topics of critical importance to IFCO members that need addressing in timely ways continue to crop up. For example: the realities of crisis and how people and families manage while living in chronic crisis states and waiting on lists. This includes the different ways we view crisis and live through crisis depending on who and what is in our lives. We know that having independent facilitation and planning, relationships, family connections, flexible individualized funding and community involvement are key ingredients for people and families living with disability that would and do make a difference in this regard.

We encourage you to come out to our next IFCO meeting where we discuss some of our agendas for the future, priorities in the short term, and also map out meetings dates and working groups for the next few months. Reaching the finish line may be a blurry reality for us at this point – but inching forward is not – we need to keep inching forward. Thank you for all your support of the message and work that the Individualized Funding Coalition for Ontario continues to stand for . . . let's inch together!



Michelle Friesen,
Co-chair, IFCO (*on behalf of the Leadership Team*)