



## INDEPENDENT FACILITATION DEMONSTRATION PROJECT

# London Community Gathering

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## Introduction

People from London, and two people from St. Thomas, attended a gathering to explore the concept and practice of Independent Facilitation, with the desire to develop community capacity to deliver this alternative service relationship.

Some of the families present have been focused on customizing support for their sons and daughters since they were very young. They have been active in school inclusion efforts, and Individualized Funding initiatives. Some families have had access to individualized funding for a very long time. Others continue to have very little available to them, but have a deep desire to access individualized support options for their family members.

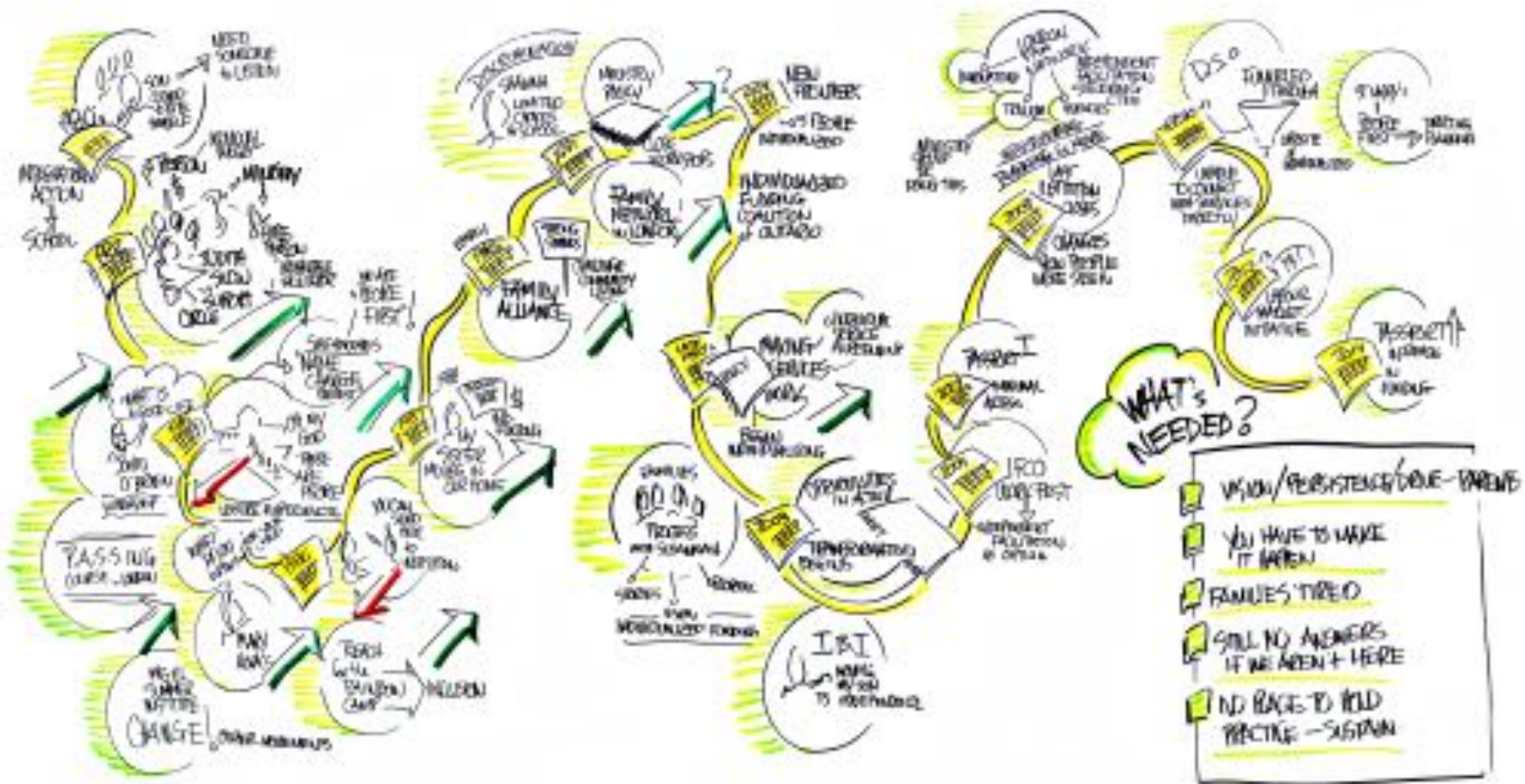
There were participants present who work in local service agencies, and have been active in delivering individualized support, and as allies to individualized support initiatives in the London area. There were agency staff present who became aware of Independent Facilitation through a training session provided by John Lord in Hamilton, ON.

Organizations represented included:

- London Family Network
- Alice Saddy Association
- Participation House Support Services
- Hutton House

One parent made it very clear that the “independent” notion he is most interested in, is his son’s ability to achieve greater independence, choice, and control. He pointed out that we need to listen to the person and their family and focus and track the progress on the desirable outcomes that can occur in their lives. It is not about tracking the service so much as paying attention to the life that changes as a result of the service.

# A Lifeline: What Is Inspiring Independent Facilitation in London?



Participants looked back over the history of challenges they experienced to create individualized solutions for themselves as people living with a developmental disability or for their sons and daughters. This group process, known as a Lifeline, asks people to consider “watershed” moments – points in time when something happened that:

- moved people **forward** in the direction of their vision (people being individually supported to live as valued, unique human beings, who are citizens)
- set people **back** moving away from the desired future of their vision

Some participants shared a very personal perspective related to their specific experience and situation as an individual or family member, and others reflects upon more global stories or experiences in the province that had an impact, positively or negatively. Overall it has been a 35 year struggle to develop the capacity to deliver customized support for individuals, with no solid systemic response, and very little practical service offerings available.

- **the early 1980s:**

- One family experienced how their son, in a school cafeteria situation, had other students coaxing him to become anxious when his mother was visiting the school...students knew that his anxiety would lead to him bite himself. It was a cruel act, and his parents knew that he needed someone who could listen to him, help him navigate his experiences with others, and assist in shaping the environment to address this kind of cruelty. They realized they could not simply expect that he would be OK. They would have to take charge of making sure his environment would work for him.
- **1982**
  - People in London became aware of Judith Snow’s story, the support circle she created of people who listened to her, and assisted her in advocating for individualized funding. Judith became the first person to establish a fully customized support system, complete with funding that she could control.
  - A local Ministry staff person was inspired by Judith and her story, and figured out a way to make funding available for someone to be hired in a role to support her, that has much resonance with Independent Facilitation.
- **1985**
  - John O’Brien was invited to London to facilitate a workshop on “What Makes A Good Life?”, reflecting the early developments of person centred planning as a means of moving toward a meaningful life as a citizen.
  - Institution closures shone a spotlight on the inhumane treatment of people with developmental disabilities, causing people in the service world to begin rethinking how we treat people, and how services should be organized.
  - Mary Kovacs (a pioneer in the concept of person centred planning) supported one of the families present, making it clear that their focus needed to be “what do you want for your child?” and “never accept the limitations of the system as it exists”.
    - Sadly, families shared stories that they are still being advised that they can send their newborn children to institutions.
- **1987**

- One family member identified that her sister moved into her family home with her husband, and had an individual budget available for supports.
- **early 1990s**
  - Family Alliance Ontario (born out of the experience of families who fought for integrated education), a family advocacy organization, presented strong stands that challenged the segregated services provided by Community Living organizations throughout the province.
  - London Family Network was formed by parents who fought for inclusive education, with a focus on inclusion, community, non-segregated/congregated supports and services.
  - MCSS developed policy calling for the closures of sheltered workshops.
  - A small organization called New Frontiers was formed to customize support for 5 individuals.
  - The Individualized Funding Coalition of Ontario formed to push for access to individualized budgets that would enable families and the people they love to plan and act on customizing their support system.
- **late 1990s**
  - Making Services Work For People, an MCSS policy initiative was developed with the intent to begin to shift accountability away from programs and focus on accountability for individual people's lives and support.
- **early 2000s**
  - Susannah Joyce supports a small group of parents, including some participating in this gathering, in a process of sharing and articulating stories; clarifying a desirable vision of the future; and developing individualized funding proposals to the Ministry that were approved.
  - One parent shared how access to IBI (Intensive Behavioural Intervention) therapy for her autistic son had a huge impact on his ability to develop independence.
- **2003**
  - The Ministry develops the "Opportunities In Action" policy paper to mark the beginning of the "Transformation Process".
- **2004**
  - Individualized Funding Coalition of Ontario sponsors a "WorkFest" Conference. Independent Facilitation highlighted as valuable role in supporting people and families.
- **2005**
  - MCSS introduces Passport as a means for people and families to access some financial resources to apply to supports and services in an individualized way. Initially limited access for people and families.
- **2009**
  - Last institution for people with developmental disabilities closes in Ontario. Individualized planning was used in preparing for people to move out into the community. Raises consciousness about thinking about one person at a time.
  - London Family Network participates in Independent Facilitation Steering Committee
    - parents develop funding proposals for Innovations Grant and Trillium

- received Innovations Grant
- Trillium declined proposal and indicates that “government should that “ be funding this”.
- **2010-11**
  - DSO system established
    - families feel as though “we are funnelled through” and that it is a “black hole of information”
    - opposite of an “individualized” experience
    - families prevented from contacting agencies directly to seek individual solutions that can work for their family and loved one
    - families need a way to find each other and build connections, share information that the DSO system blocks from happening
  - Community Living St. Mary’s explores “person directed planning” initiative with People First members as facilitators of the conversations.
- **2012-13**
  - Labour Market Initiative ran in Thames Valley with between 25 to 28 facilitators. Some people continued to facilitate voluntarily for some time, after the project ended.
- **2014**
  - MCSS increases Passport funding, with broader availability. Still, families have to facilitate this funding themselves, with little support and no infrastructure for sustained individualized support.

In London, there has been a long history of people’s interest, awareness, and action regarding individualizing support for people with developmental disabilities. Small numbers of people, with their families have been able to pursue these kinds of customized support options, with resources and individualized funding, but no systemic, or broad access to these options.

Families articulated that anything that has happened in this vein has required the vision, persistence, and drive of families to push it forward. Families are tired to the point of exhaustion: not only from the work of having to sort out how they will find ways for their family member to receive any kind of support each week (168 hours in each week that families are now totally responsible for figuring out after school no longer occupies 30-40 hours each week), including having to navigate a difficult, confusing, maze of the adult social service and health systems; but they also are having to explore creating new options for services since the existing services still predominantly offer congregated programs, and even these have wait lists.

Neither MCSS, or existing service agencies have taken the lead on making customized individual options possible. There still are no options or offerings available without families making them happen.

Families articulated that there is a need to have some place that holds this vision and practice of imagining and developing customized support; and some people, beyond families, who can help ease the weight and lions share of sorting out how the person they love can live life as a fully contributing citizen. Many families present have been active for a long time. While the 20, 30, 40 year journey with no solid solutions in sight, has made families tired, the urgency to have something available as they face getting older continues to drive them to find solutions.

One self advocate mentioned a high school experience she had that serves as a metaphor of what it is like for people with developmental disabilities...

- *She had thought a lot about the kinds of things she wanted to do later in her life. She thought about the kinds of things she wanted to learn about in relation to her future and her interests. She looked through the offerings in her school course calendar, and picked the ones that she wanted to take. She made a plan. She told the school teachers and counsellor about her class choices. She was told that those classes were not available to kids like her. Then she was told which classes she would take. She was quite aware that other students got to choose the courses they wanted to take. She said, "That's discrimination!". This is symbolic of planning without access, or the resources and support available to follow through on the plan. The school made no effort to think about how she could follow through on what she wanted to learn about, and support her to do that. They simply told her what was and was not available to her. Planning without the support to follow through, simply breeds disappointment, leaving people feeling that they are less valuable than other people. This same self-advocate pointed out, "We have feelings too!", to get at the point that these kinds of typical system responses actually hurt a real live human being.*

# Understanding What Independent Facilitation Is In Practice: The Ongoing Journey Across The Gap Between Current Reality And A Desired Future

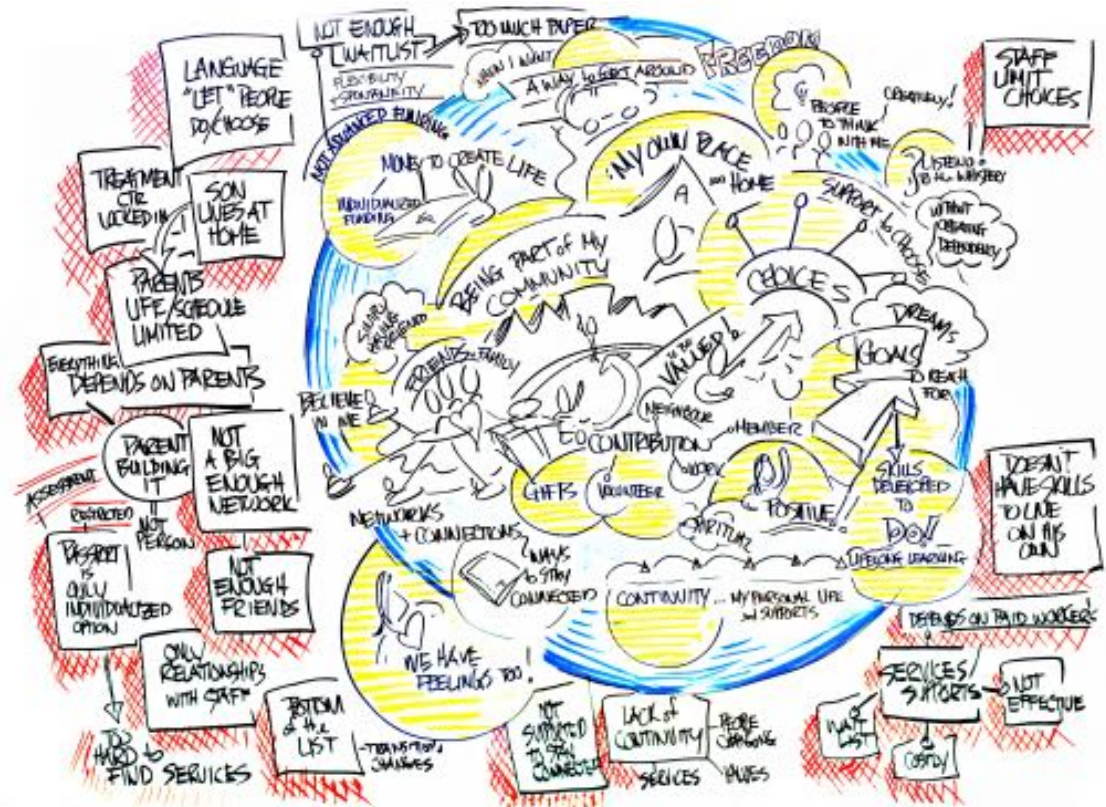
## THE GROUP'S STORIES THAT EXPLORE WHAT INDEPENDENT FACILITATION IS ABOUT

Participant were invited to:

- Think of a person with a disability who they knew well enough to have a sense of a life that would:
  - make them happy
  - engage them
  - provide a sense of purpose
- draw, with pictures and words, a picture that captures this desired life
- in small groups, make room to listen to each other's vision of this life they have drawn
- have a conversation about what they noticed these stories had in common — choose 2 or 3 of these ideas to share with the larger group

In the large group we created a composite image using the common ideas shared in the small groups.

We then asked the group to state what the current reality is like in relation to this desired future life.





A narrative summary of the of the composite picture is captured in the table below:

Desired Future	Current Reality
<p><b>A network and connections</b>...people will have a network of people who they know, relate to, and belong with. They will know people and thereby have connections.</p> <p><b>Simply having friends</b>...mutually supportive, caring relationships, free from “payment”, relationships where the benefit and joy comes from knowing, and being with each other.</p> <p><b>People who believe in me</b>...to have people who believe in my worth, and that I “CAN” do and learn many things that I choose to do and learn.</p> <p><b>Listened to</b>...people will have someone who can and will listen to them, to their dreams and visions, their goals, their struggles... someone other than their Mom or Dad, someone who can listen and then support them to move toward the things that are important to them.</p> <p><b>Ways to stay connected</b>...to be supported to stay connected to people who are important, family who is not close by, friends that are not as available as they once were, support people who were close but who have moved on to other jobs.</p>	<p><b>Network is not big enough</b>...right now too many people have a very limited network, often just their family or people associated with programs they attend.</p> <p><b>Not enough friends</b>...if they have any friends, they do not have many.</p> <p><b>Staff are only friends</b>...many people who live in residential programs or attend day programs will speak of staff there as the only people they think of as friends. While staff may have “friendly” relations and like working with people, they would not likely consider this person as their friend, who they would spend time with when they are not working.</p> <p><b>Not supported to stay connected</b>...when receiving services, often people are not supported to reach out and stay connected with people who are important to them. An example was given of a person whose parents died, but they were not supported to stay connected with brothers and sisters.</p>

Desired Future	Current Reality
<p><b>“My own place” that is my home</b>...having a place that people choose as their own, have control over, able to decide who is welcome, and create as a safe place.</p> <p><b>Being a part of the community</b>...not just living in the community but actually participating as a member of the community, a neighbour, a citizen.</p> <p><b>Faith and spirituality</b>...to have, and to be seen to be someone for whom faith and spirituality is important. To be a member of a faith tradition.</p> <p><b>Be valued</b>...to be seen as someone who is valued, who is recognized for what they have to offer.</p> <p><b>Be positive</b>...one self advocate said that it was important to be positive, to have a good outlook on life.</p> <p><b>Making contributions</b>...to actually participate in the community, and in relationships, in ways that bring value to other people.</p> <p><b>Recognized as people who have feelings</b>...at a very basic level, people will experience empathy and compassion from other people who recognize that they are people who have feelings.</p> <p><b>Transportation— ways to get around</b>...to have ways to get around that allow people to participate in the things that are important to them: work, social gatherings, shopping, visiting friends and family. That these ways of getting around are available when they need them, and accessible.</p>	<p><b>Son lives at home</b>...for many families, their adult sons and daughters live at home with their parents well into middle age.</p> <p><b>Locked in treatment centre</b>...one woman shared that a person who she works for is currently locked up in a treatment centre with no freedom to leave.</p> <p><b>Does not have the skills to live on his own</b>...one parent spoke of how her son had been able to apply and be accepted into a college program, including residence, but he did not have the skills developed to do it on his own, and there was no plan for how he could be supported to do this.</p>

Desired Future	Current Reality
<p><b>Supported to dream</b>...to have people in their life that help them to learn and practice dreaming, to imagine more.</p> <p><b>Have people who can think creatively and plan with me</b>...to have people in their lives who they trust and respect, who can listen, think, share ideas and resources, and be willing to make connections to help move a plan forward.</p> <p><b>Goals to reach for</b>...to always have something that people are working toward, something to accomplish, something that inspires learning and growth.</p> <p><b>Having choices</b>...people will have a real set of choices, a range of options. They will have experiences that let them know and understand the choices that are available to them.</p> <p><b>Money I can control to create my life</b>...to have enough money to take care of life — home, transportation food, clothing, interests , etc.; and money for support that they can control and use to follow through on plans.</p> <p><b>Supported in learning how to make choices</b>...people will be supported to learn how to make choices, they will learn about consequences, things that can happen when they choose, positive or negative. The purpose of the support in making choices is to increase skills so as to not create a dependency on the person who is supporting them.</p> <p><b>Continually learning and developing skills</b>...to be seen as someone who can continue to learn and gain skills to be able to be more responsible for living their own life.</p>	<p><b>Everything depends on parents</b>...in many situations absolutely everything depends on parents to make things happen, to struggle to get resources from government; to find, hire, train, and manage people who can support their son or daughter; to providing transportation; to making connections in community; to starting organizations; to dealing with the health system; and the list goes on and on...</p> <p><b>Parents lives and schedule are limited</b>...when an adult son or daughter who requires support lives at home, the schedule of parents is tied to what their son or daughter needs. Sometimes this means that parents become really confined and unable to live a life of their own.</p> <p><b>Parents building life</b>...not the person. Often the person has not had the chance to be supported by people who are their parents to build their own life, their parents have been responsible for making everything happen.</p> <p><b>Passport is the only source of individual budget</b>...for people in London, Passport is the only source of individualized funding available. For the most part people and their families would say that the amounts are not enough to truly create an individualized support system, and as result people often find themselves having to “buy time” in segregated programs.</p> <p><b>Staff (and families) can limit choices</b>...for people who live in or attend agencies, or remain living at home with their parents as adults, often the people who are responsible in their lives (staff and parents) actually limit the choices that people have. Sometimes this is because they cannot see how they could make something happen, or it could be because they do not recognize the person’s capacity, and might believe their desires are “unrealistic”.</p> <p><b>Language of “let people choose”</b>... staff in agencies noted that there is a fundamental recognition of the lack of power that people have, when we say we “let people choose” from limited options.</p>

Desired Future	Current Reality
<p><b>Continuity in life and supports</b>...people wish for some continuity in their lives, in relationships with friends and family, some support staff who stay on with them, funding that is not always changing, places to go that are familiar, so that when there are things that change, not everything will change at the same time.</p>	<p><b>Lack of continuity</b>...families, and the people they love experience a constant break in continuity in their lives in relation to their support. Changes in staff from agencies, or the DSO, or when they do self-hires, and changes to policies, regulations, procedures, all leave families in a constant state of upheaval.</p> <p><b>Hard to find supports and services</b>...even when people do have financial resources to be able to use, families find it incredibly difficult to find the people and services that truly link with their desires and needs for support that suits the person.</p> <p><b>Services are</b>...not effective, costly, or they are put on a wait list. People find that what is available is not always helpful. Families are left to do a lot of work to think about and act on the things that these services are either unable or unwilling to deliver on.</p> <p><b>Depends on paid worker</b>... one parent identified that when families are looking for support, the services pay too much attention to the staff as a solution, creating a dependency on staff, and not focusing enough on developing skills for independence, or connections with people who are not staff.</p> <p><b>In transition</b>...each time that someone moves through a transition that requires new supports, they go to the bottom of the list with everyone else who is waiting for those same services.</p>

**Independent Facilitation** is the work of supporting people over time as they move across the gap between current reality, and a desired future where people can be happy, safe, engaged and recognized as valued contributing citizens. It is “Independent”, meaning that it is not attached to or limited by the constraints of the existing service system programs. Independent Facilitation involves:

- meeting a person where they are at
- listening to the person — this involves discovering the way that they communicate, and paying action to things like:
  - what is important to them

- who is important to them
- what would they imagine for their future
- what are their gifts, capacities, and contributions
- what brings them joy and happiness
- what kind of support do they need
- getting to know their family, and helping the family listen to the person
- learning about their current reality
- facilitating planning for action to move toward a desired future
- support in finding and accessing resources that make it possible to move forward, including:
  - funding programs:
    - disability specific
    - other focused (e.g. housing, employability)
  - community resources available to all citizens
  - people, places, and groups that can offer participation and/or support
- supporting the person and their family in exploring decisions and the potential consequences and responsibilities that are involved.

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## Steps to Move Forward...

- **Establish Committed Leadership Group/Steering Committee:** Convene small group of people who are willing to reactivate leadership ...**Patricia as Lead**
- London Family Network and Steering Committee:
  - develop **vision** for Independent Facilitation in London
  - develop **plan** for moving forward
  - identify **leadership roles** necessary to carry out the plan
  - **leaders who will commit** to take on key roles
  - **leadership and vision** of people and families
- **Connect with OIFN Stewards** (Marlyn Shervill and Judith McGill) to identify role that OIFN can play in supporting London initiative.  
**Diana as Lead**

### Upcoming Opportunities:

The group was encouraged to:

- sign up for updates and news about Independent Facilitation on the [oifn.ca](http://oifn.ca) website (at the bottom of the Home page)
- Save the Date for the upcoming OIFN “Common Threads” Conference to be held Nov. 16-17, 2016
  - bursaries may be available for families and people with disabilities
- OIFN Southern Forum to be held in February 2017

## APPENDIX I: Diana Brammall's Story of Independent Facilitation in Her Brother Tyler's Life

### Diana Brammall – Team Tyler

Our family started the IF process in 2014. We were a little skeptical in the beginning as my brother doesn't communicate like everyone else & is hearing impaired. Meetings that focus on conversation usually cause him to take off his glasses & put his head down for a nap. Our facilitator visited us at home and we met with her at Tim's a couple of times. She always arrived with cookies from Tim's so Ty eventually called her the cookie lady. The cookie lady helped us figure out what Ty wants to do with his life.

One of the goals we are working on is expanding my brother's natural supports. Tyler has identified that he would like to visit our family in Nova Scotia. Nova Scotia still has institutions for those with developmental differences, so the explanation of independent facilitation had to be clear in order for our family to understand what we were trying to accomplish.

I explained that independent facilitation is fancy way to say we are helping people plan their lives. I explained that each of us has a circle of support around us. We may not be aware of it but when we sit down and discuss how we are supported; we can easily identify those who are important in our lives. Independent facilitation helps us to identify our natural supports such as family & friends & helps us determine how much paid support is required for an individual to live as independently as possible. IF also helps the family create a budget that can be submitted to DSO.

When my brother was graduating from High School last June, we contacted DSO and arranged a school transition team meeting. We lived in Chatham Kent at the time and the only services available to him were agency based. The supports consisted of a day program that is basically a glorified babysitting service, also known as a sheltered workshop. There is very little work so clients socialize and colour every day. We were also offered respite through the same agency. The respite home had holes in the wall, one computer that clients weren't allowed to access and due to funding cuts, outings in the community were not a part of a respite stay.

The sheltered workshop and respite service were never a part of my brother's life plan that he created with the cookie lady. I was also acutely aware that due to my own health, it was going to be a huge struggle to provide him with 24-7 support. My husband and I were forced to look at our own life plan and quickly realized that our retirement goals were in conflict with giving my brother the opportunity for true inclusion in the community. So, we listed our house for sale and rented an apartment in London.

We brought him to tour each of the programs that he expressed an interest in. When we met with Community Living, the first question we were asked was if Ty was on the housing wait list. Needless to say, Ty wanted nothing to do with Community Living when we finished that tour. Tyler chose the programs he liked & is now accessing programs & services all around London. Many of the programs are segregated, such as Hutton House and the Life Skills Centre but he is also involved in programs that are not segregated such as a clay class at the Clay Arts Centre. Our goal is to help him move into community over time at his own pace and comfort level. We moved here last Nov and he has already decided independently that he wasn't enjoying the two programs on Tuesday's at Hutton House. Along with his new support staff & support circle, he decided to volunteer at a thrift store and now does a half day there on Tuesday instead of going to Hutton House. That is success!

Tyler has always been an avid 5 pin bowler and played on a special needs team the seven years we lived in Chatham Kent. He also played on a "regular" team when he was a child growing up in Brampton. When we went through the independent facilitation process, the cookie lady

suggested that Ty could try a regular bowling league and not a segregated league. On Wednesday nights from Sept to April, he is a member of the “Get A Life” team at Fleetway bowling centre. When people ask me what the biggest difference is between individualized planning and agency planning, bowling is the example I give them. Community Living offers a segregated bowling program at Fleetway on Wed evenings and that’s the same evening that Tyler bowls but he starts at a later time. Tyler is arriving to bowl as the CL participants are leaving. For me it represents a metaphor of individualized choice and agency choice. In 10 years from now, my brother will have built natural relationships on his bowling team with people who are not paid to be with him. In 10 years from now the segregated participants will still be segregated with paid support staff.

For Tyler the Independent Facilitation process ensures his voice is heard and he is the central figure when determining his future. For my husband and I, it gives us piece of mind for Tyler’s future care and I no longer worry about my brother being lost in the system.



**Ontario** Ministry of Community and Social Services  
Community and Developmental Services Branch

This event is facilitated by the OIFN with support of the Ministry of Community and Social Services (MCSS) through funding of the **OIFN Independent Facilitation Demonstration Project (IFDP)**