



weaving a story of change

The Independent Facilitation Demonstration Project



learning so far...

ontario
independent
facilitation
network
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learning so far...

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introduction

There are an estimated 70,000 people with developmental disabilities in Ontario. Fewer than 20,000 have spaces in agency directed residential settings; most of them require day/employment support on weekdays as well. By 2018, 24,000 people will access PASSPORT direct individualized funding to enable people to create more customized support.

The Space for Independent Facilitation's Contribution:

The current system generates two tensions that define the space for Independent Facilitation's contribution:

Tension 1: The Government offers two different funding arrangements to people and families.

Arrangement one: The Ministry contracts with agencies to offer a minority of people a combination of residential and day/employment programs to provide single answer to 24 hour support when their turn comes on a wait list. Even though a significant amount of new investment goes to increasing the number of residential beds, there remains a significant shortfall which is likely to continue.

Arrangement two: The Ministry offers the opportunity for people to receive direct individualized PASSPORT funding, so they and their families can develop a customized model of support. This involves organizing their available personal, family and community assets and Government benefits, both generic (income support, employment services, health, housing, etc.) and developmental disability specific.

It is important to note, that the average PASSPORT allocation

(significantly less than \$35,000) per person falls well short of expenditures on agency directed residential/day/employment service combinations (more than \$100,000).

Making the best of the PASSPORT option takes significantly more work on the part of people and families to plan, mobilize, access and sustain the constellation of assets that support a good life. It is facilitating this work across a spectrum of family and community differences that has shaped the work of Independent Facilitation.

The Independent Facilitation Demonstration Project (IFDP) has demonstrated that real progress can be possible even while people are waiting for PASSPORT funding. This increases the focus and impact of individual funding when it comes.

Tension 2: Most agency's struggles with transformation absorb a great deal of attention and open a space for people and families to innovate that cannot be managed from the top.

Despite growth in individualized funding, agency directed group service designs consume the larger share of expenditure on developmental services. The Ministry, and each of its funded agencies, manage a tension between maintaining agency capacity to offer good group oriented supports and developing agency capacity to transform its offerings to implement the Social Inclusion Act (SIPDDA).

For those people and families who choose it, individualized

funding creates a space outside this agency based work for person and family driven innovation, both individual and collective. This is the space in which Independent Facilitation makes its most significant contribution.

The process of Transformation requires a new capacity to invest in local innovation, created by people, families and allies. These investments recognize that person-directed innovations are different from innovations designed and implemented by agencies and call for new ways of assuring accountability, sharing learning and sustaining what works.

The Ministry has recognized the movement towards social inclusion and self-direction. Some people want individualization for places to live, work, and participate as a valued community member. These desires call out for significant investments in the relatively uncharted territory of person-community level innovation.

There is no ‘silver bullet answer’. Individually crafted responses through Independent Facilitation are a viable option for many people who are difficult to fit into traditional program models, or just don’t want to “fit”.

Calling For New Collaborations

The Ministry, service providers, individuals, families, advocates all agree new options are needed. Since future options are not yet clear, there need to be new safe spaces to generate cross boundary agreements on potential options. The boundary issues include health, child welfare, corrections, addictions, mental health, family supports, aging, dementia.. and more. Although indigenous issues add additional layers of jurisdictional complexity - none of these issues will go away or be ignored. Responses limited to

narrow silos will only add to the chaos and frustration.

Innovative options such as Independent Facilitation are not ‘THE answer’, but they are a key element in a family of responses - new and old - that desperately need to collaborate so that citizens have genuine opportunities to contribute.

People WANT to be contributing citizens in and of the community. Agencies of all shapes and sizes WANT to support people and families to be fully participating citizens. The Ministry WANTS to liberate and support the capacities of citizens who have historically been excluded to be fully engaged citizens.

To create this feasible future, there must be collaboration on a scale we have not yet seen. It will require mutual trust, respect, transparency - AND funding. Endless ‘projects’ that create glimpses of hope only to fade into oblivion, erase the very energy and trust that can build this desirable future on which we fundamentally all agree.

The Independent Facilitation Demonstration Project’s learning journey to Weave A Story Of Change outlines the history, complexity and possibility of creating and sustaining the contribution of one innovative option of support.

We believe it has enormous potential - **if** it is funded and supported appropriately. It is NOT a silver bullet. It is only one of the family of new options that we can and must develop to create better and secure lives for disadvantaged citizens.

We must ultimately create support structures that are sustainable so we do not betray the hopes and capacities of people once again. This will not be easy - but it is possible.

who is this document for?

...people with developmental disabilities, their families, and allies -- to help them understand what Independent Facilitation is and how it might be able to help them in create the life they need and want

...the Ministry of Community and Social Services -- to support its efforts to transform Developmental Services and make a case for Independent Facilitation as a valuable investment in innovation that supports MCSS vision to develop services that enable people to be included and belong; to contribute as community members; and live as citizens equal to all other citizens

...DSOs -- to provide a clear understanding of what Independent Facilitation is and who may benefit from this type of service offering.

...anyone who is interested in becoming an *Independent Facilitator*

language we use

In this report we will use the following language:

“people” - people with developmental disabilities.

“families” - people who have a family member who has a developmental disability... “families” can also include parents, grandparents, brothers and sisters, aunts and uncles etc. Family can mean a person who feels a deep sense of love and responsibility for a person with developmental disabilities.

“allies” are people who stand with and support people and their families as they work toward living as a citizen and community member. Allies are not paid to offer this support.

“Independent Facilitator” is a person in an ongoing relationship with people and their families, together planning for and developing individualized support that makes it possible for this person to live and participate as a citizen and community member.

“Agencies” are organizations that provide direct services for people with developmental disabilities.

“staff” are people who work as a personal support worker for a person with a developmental disability.

“funding” is the money that the government makes available to people, families, and agencies to pay for supports and services.

“DSO” is the Developmental Service Ontario are organizations across the province where people and their families must go to access support that is paid for by government.

“the Ministry” is the Ministry of Community and Social Services that is responsible for funding services and support for people with developmental disabilities and their families.

“IFOs” are Independent Facilitation Organizations that offer Independent Facilitation as a support to people and their families.

“OIFN” is the Ontario Independent Facilitation Network —is an organization that involves people across the province who are interested in the work of Independent Facilitation, and how it can make a difference in the lives of people with developmental disabilities.

“IFDP” is the Independent Facilitation Demonstration Project — a 2 year project funded by the Ministry to explore how Independent Facilitation can be offered as a support for people in more communities across the province.

“emerging communities” are communities and networks throughout Ontario that currently have no access to Independent Facilitation. The Project includes preliminary contacts and future development with a focus in the near North and the North of Ontario.

“Social Inclusion Act” (2008). The law that guides the Ministry to offer funding and services to support people with developmental disabilities. Its full name is “*Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 (SIPDDA)*”

where to start reading?

The Report is divided into parts.

Each of the parts is connected to the other parts but they can be read separately.

You don't have to start at the beginning. You can pick from below what sounds most interesting to you, and start there.

INTRODUCTION

WHO IS THIS DOCUMENT FOR

LANGUAGE WE USE

WHERE TO START READING

PART A: Change, Innovation, and the Independent Facilitation Demonstration Project

This is about the history of how we see, treat, and support people with developmental disabilities. The Ministry is faced with the challenge of innovating, creating new models of support that match the view of people as citizens. The IFDP is one effort to create a viable support offering that can be one option for people.

PART B: What People Say About What They Want And Need

This is about what people and families say about what they want and need, and how Independent Facilitation is a model that responds to what people are saying.

- ii **PART C: What Is Independent Facilitation And Who Can Benefit**
- iii This is about explaining what Independent Facilitation is, through stories and descriptions. It is also about identifying who can benefit from Independent Facilitation.

- A-1 **PART D: The Challenge Of Getting Started**
This is about the efforts and challenges facing communities that want to make Independent Facilitation as a service offering in their community.

- B-1 **PART E: Looking Forward**
This is about the focus of work for OIFN going forward. It is also about the need for working together with the Ministry, people and families, service agencies, and OIFN. People and families need support to make the best use of their PASSPORT direct individualized funding to develop customized support options. There will be better innovations if we work together.

C-1

D-1

E-1

learning so far...

weaving a story of change

The Independent Facilitation Demonstration Project



Part A:
change, innovation, and the independent facilitation demonstration project

Part A: change, innovation, and the independent facilitation demonstration project

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the historical context of the IFDP

It is not possible to think about the Independent Facilitation Demonstration Project outside of a history of ongoing change and innovation in the way we see, treat, and support people with developmental disabilities.

We will put the IFDP in the context of three big waves of **change and innovation**.

(You can learn more about the History of Developmental Services at <http://www.mc当地>.gov.on.ca/en/dshistory/)

change and innovation

Life is about change. Nothing stays the same. There are times when we are sad about change and want to hold on to the way things have been. There are other times when we are happy to see things change. And there are times when we feel that we need to actively create change because things cannot continue as they are.

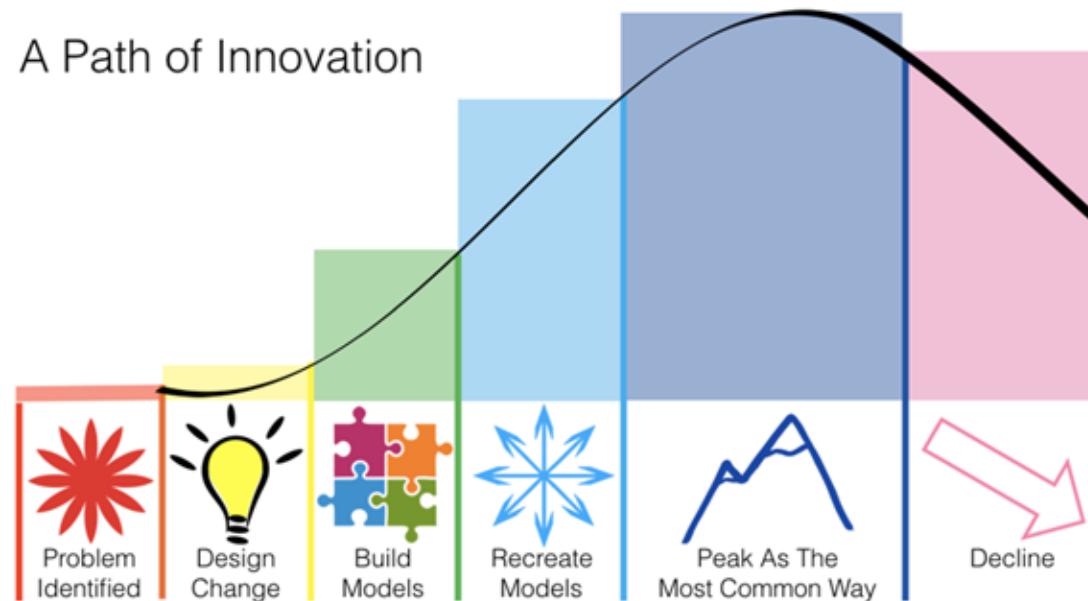
These are the times when we need to **INNOVATE**, meaning “to create change” or “to make something new”.

The Developmental Services Branch of MCSS has been actively exploring and investing in innovations that can transform the way we support people with developmental disabilities and their families.

The Independent Facilitation Demonstration Project is an investment by the Ministry in **innovation and change** that explores ways that more people can direct their lives and the support they need and want.

a path of innovation

There is a pattern to changes that come from innovation. It can be represented by the shape of a wave.



A PROBLEM is IDENTIFIED —something that people feel passionately needs to change.

People organize to imagine ideas and **DESIGN** what could create the **CHANGE**—what would it look like and what it would take to create this change.

We **BUILD MODELS** that include what, where, who, and how things will be built or created and work.

When we discover models that seem to work well, we **RECREATE the MODEL** in more places for more people. The model or way of doing things becomes more common.

Eventually the model reaches a **PEAK AS A COMMON WAY** of doing things, some models rise above the rest and are seen to be THE WAY to do things.

But eventually as the world changes, and we know more about what works and what does not. Eventually the model we created no longer does what people need and want in the way they need and want. The model **DECLINES** in its usefulness.

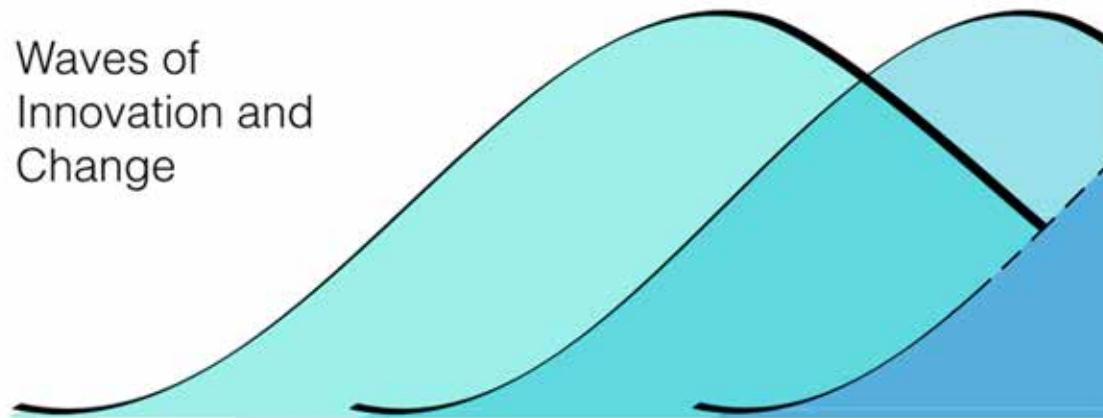
Along the way, **NEW PROBLEMS** are identified. Solutions that worked for the old problem, no longer work for the new problem, so the process of innovating new solutions and change starts again.

This work is work that local people must do. They must create and design/define “models” (patterns of response) to particular individual and family needs in this place and time. Models can not be ‘duplicated’. They can be re-created and adapted to the differing needs of new people and situations.

To be successful Independent Facilitation must, in every case, be a local innovation, led by organizing people and families and allies who care enough to overcome stress, exhaustion and cynicism, and ultimately make it happen. It cannot be imposed as a “model from above”, although it can be enabled by good investments which is described in **Part E Looking Forward**.

three big waves of change

We will look at 3 big waves of innovation and change related to people with developmental disabilities. These waves of change and innovation have occurred in many places around the world, including here in Canada.



Large Institutions	Group Programs in Community Settings	Person Directed Individualized Support
<ul style="list-style-type: none">• 1870s to 2009• people were identified as "insane" together with people with mental health issues• institutions created as more humane alternative to jail• Ministry of Health operated "hospital like" settings to:<ul style="list-style-type: none">• protect community• treat and "fix" people	<ul style="list-style-type: none">• 1950s to Present• institution conditions exposed• people first labeled with the "R" word• grouped in categories:<ul style="list-style-type: none">• educable• trainable• severe to profound• group programs created for:<ul style="list-style-type: none">• school• day activity - life skills, sheltered workshop• residential - mostly group homes• Ministry of Community and Social Services funded• Agencies directed and managed programs<ul style="list-style-type: none">• protect people from community	<ul style="list-style-type: none">• 1970s ...still emerging• "normalization" and valued social roles• citizen advocacy• self advocacy —"We are PEOPLE first!"• "support circles"• inclusive education for ALL children• person centered planning• direct "individualized" Ministry funding to people and families to create individualized support<ul style="list-style-type: none">• SSAH for families (1982)• Passport for adults (2008)• independent "Broker" role developed in Windsor and Thunder Bay (mid 1990s)...later to be Independent Facilitator

"When you
know better,
you do better."
*Annie Henderson
(Maya Angelou's
grandmother)*

The way we see people has shaped the solutions and models of support that we develop. It is important to note that time and budget allocations are consumed in the second wave, and the new third wave of transformation struggles to squeeze into the budget cycle.

LARGE INSTITUTIONS

(late 1800s -2009)

It is sometimes hard for us to believe, but the creation of large institutions in the late 1800s, was an innovative change.

“...society didn’t differentiate between people with mental health issues and those with developmental disabilities. They were all deemed to be “insane”. Families looked after them as best they could. But what if they had no one? In early Upper Canada, the only place for them to be placed was in the common jail”

*From institutional to community living:
A history of developmental services in Ontario*

The conditions in the prisons and jails were terrible for all people, but the experience for people who were known as “idiots, lunatics, imbeciles, the feeble-minded and epileptics”, were worse than all the rest. Eventually the government recognized that these people did not belong in jail. The awareness of this profound problem of human suffering, caused the government to look for new ways of treating people.

The government turned to the doctors who considered,

“a disability (w)as a flaw in a person that needed to be corrected through appropriate training and modification, preferably in large hospital-like settings situated away from mainstream society.”

*From institutional to community living:
A history of developmental services in Ontario*

Institutions were “hospital-like” settings created as a more humane alternative to jail.

The institutions were designed for two purposes:

- to protect the community from people with developmental disabilities;

- and to “train” and “modify” the behavior of the people who lived in the institution.

The Ministry of Health developed and managed institutions until the 1960s.

By the 1960s the dehumanizing treatment of people living in large institutions was exposed. The public and the government recognized the need to find a new, and more humane, way of supporting people.

Institutions began to change in the 1960s and the model of large institutions peaked in the 1970s, and declined as people were moved out and group programs in community settings grew. In 2009 the last institution was closed, more than 130 years after the first institution was opened.

“I offer an apology to the men, women and children of Ontario who were failed by a model of institutional care for people with developmental disabilities. We must look in the eyes of those who have been affected, and those they leave behind, and say: We are sorry.”

Kathleen Wynne
Premiere of Ontario
Dec. 9, 2013

AGENCY DIRECTED GROUP PROGRAMS IN COMMUNITY SETTINGS

(1960s to present)

“... I think it is time something was done for parents, who, from a sense of faith and hope... want to keep [their children] at home, living a normal life. These are real parents, only asking a little aid and encouragement... may the Ontario government help them and their children...”

Victoria Glover, Grandmother
Toronto Star 1948

There have always been parents and families who kept their children living at home with their family. In the 1940s, 50s, and 60s, groups of these parents formed “associations” working and advocating for their children. They worked to provide schools and classrooms for their children in their homes, churches, and local community spaces. While “special education” was developed during this period, children with developmental disabilities were not included. Children with developmental disabilities would not have the right to an education until 1980.

The medical profession changed the way it saw and treated people with developmental disabilities. The painful label of the “R word” was used during this period. People were classified or grouped according to 3 additional labels associated with the “R” word — “educable”, “trainable”, or “severe to profound”.

Parents advocated for education and services in the community for their sons and daughters who lived at home. Eventually the government responded by providing funding for organizations to develop services and supports in the community.

Programs were organized and funded in two broad categories:

- group “day” programs — life skill programs, sheltered workshops
- “residential” programs, mostly group homes.

People's lives were divided between where they spent their days during the week, and where they lived the rest of the time.

Agencies directed and managed these group programs in the community. Programs in the community were seen as an alternative to large institutions. These programs were designed to provide "safe" places, that would protect people who were seen to be vulnerable, from a community that did not appear to be welcoming.

Agency directed group programs in community settings remain as models that receive the largest investment from the Ontario Government.

PERSON DIRECTED INDIVIDUALIZED SUPPORT

(1970s ...still emerging)

A rich era of ideas and movements grew in the 1970s-80s, built upon the radical common sense view that people are human beings and citizens.

Everything is connected. Bengt Nirje introduced the concept of “**normalization**” after the dehumanizing treatment of people in institutions was exposed in the 1960s.

“The normalization principle means making available to all people with disabilities people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society.”

John O’Brien explains a significant contribution of Wolf Wolfensberger’s analysis, and understanding of the “**valued social roles**” of citizens, that exposes,

“...the powerful and mutually reinforcing connection between how society sees people with disabilities, the shape of the services professionals consequently offer, and the impact of these services on the lives of people who rely on services.

He (Wolfensberger) illuminated the practical differences it makes to understand people with disabilities as citizens and developing persons rather than as sub-human, as menaces, as objects of ridicule, as sick, as burdens of charity, as eternal children, or as holy innocents. This perspective offers a powerful tool for deconstructing common service practices and points a way to improve life conditions by emphasizing personhood, citizenship, and developmental potential.”

These new ways of thinking fostered a change in the way we see people, and how we think about supporting people in ways that respect their individual humanity.

Safety for people who are vulnerable depends on personal relationships. O’Brien identifies another contribution of Wolfensberger in addressing the deep concern of

“An institution is not just a place, it is the way people think..”

Pat Worth
Founding Member
and Past President
People First of Ontario

parents,

*“...for who will look after their son or daughter’s interests when they are no longer able to do so, Wolf’s experience of the importance of positive personal relationships in any effort to assist vulnerable people led him to conceptualize **Citizen Advocacy** in an intuitive leap. In this form of protection and advocacy, a competent citizen enters an unpaid, freely chosen relationship with a vulnerable person and represents that person’s interests as if they were his or her own.”*

Citizen Advocacy Ottawa was formed in this era.

The **self advocacy** movement organized to change the way people with developmental disabilities are seen and treated. People First spoke out about being seen and treated as PEOPLE, first. They wanted to live in the community and be involved as neighbours, workers, community members, and friends.

Self advocates spoke about the harm that came from being labeled by the “R” word. They protested to eliminate the name of the “Associations for the Mentally Retarded”, and change it to “Associations for Community Living”. A new clear focus was on the right to be supported to live as a valued citizen and contributing community member.

Judith Snow, visionary, philosopher, activist, and artist, shared her experience with friends, her **support circle**, who saved her life by liberating her from a chronic care hospital, enabling her to be the first person in Canada to access individualized funding that made it possible for her to live in her own home with the support of personal attendants that she chose. Ultimately, this made it possible for Judith to make a difference for people around the world.

The government recognized the need to support families who keep their children at home. The **Special Services At Home (SSAH)** program provided individualized funds directly to families to develop and hire individualized support for their sons and daughters to live at home and participate in their community.

In 1980 the new **Education Act —Bill 82**— finally provided the right to an education for ALL, including children with developmental disabilities.

The **Inclusive Education** movement was led by parents who wanted their children to go to their local neighbourhood schools with their brothers and sisters and neighbours. They wanted their children to be included, to learn and grow as members of their community with all the other children in their neighbourhood. They wanted support to be provided to the regular classroom.

Person Centered Planning (now referred to as Person Directed Planning) grew out of a desire to move past the medical and educational “labeling” process, to recognize people as unique and valued human beings, and support communities and schools to discover ways to organize, welcome, and support the unique gifts, contributions, and skills of a person with a disability.

In the 1990s parents and families, joined with self advocates, to form the Individualized Funding Coalition for Ontario (IFCO). The Coalition advocated for government to provide **“individualized funding”** for adults and their families. Families had become used to designing support for their loved one using the SSAH funding, and wanted to extend and expand this model into adult life. Self advocates just wanted to control their own lives, and live as citizens.

The language of **“self-determination”** grew out of a recognition that people with developmental disabilities are citizens, equally deserving of the opportunity to direct their own lives, as all citizens do.

The Ministry recognized the challenge that self-determination and individualized funding posed on a system designed to support people as groups:

“There is an identified need for cultural change related to “new ways of doing business”, including training for families and staff, and transition strategies to support organizations... centering on the person

requires a change in the values, knowledge, and skills throughout the system a single focus on staff training will not be sufficient to create the changes in values and knowledge Many agree that this process of change would be much easier if everyone could “start from scratch”.

Shifting Power and Control:
Moving from Programs to Support
MCSS 1994

In the 1990s three communities (Windsor-Essex, Thunder Bay and Toronto) partnered in projects with the Ministry to develop new ways of doing things that focused on:

- individualized funding for people
- individualizing support for people that they can control (with the people who love them)
- a “Broker” role for ongoing support in person directed planning for action and developing support that connects people and their families to community resources, places, groups, and relationships
- the “Broker” role served as a model that would later be called “Independent Facilitator”, someone who is independent from the traditional service agency program models. Facilitators work “to make it easier” for people and their families to develop individualized support that creates the changes that they need and want

the origins of the independent facilitation demonstration project (IFDP)

The Ministry has developed ways of providing direct funding for people and families through SSAH for families with children and Passport for adults to serve the new wave of ideas related to “Person Directed Individualized Support”.

Service Agencies face the challenge of changing their entire organization structure, culture, and practices to shift from agency directed, group/category programs (residential, day, employment), toward person directed individualized support models. Agencies across the province have been tackling this transformation with greater or lesser success. There are many obstacles to this change, including the way the Ministry provides funding to these agencies; families who do not want the existing models to change; staff attitudes and vision of people with developmental disabilities; organization routines and practices that are not developed to support individual choice and control.

Windsor-Essex Brokerage for Personal Supports (WEBPS) continues the work that began in the 1990s. WEBPS survived past the initial “pilot project” phase of the 1990s because of the strong, creative, local working relationships established between WEBPS, People First, Windsor-Essex Family Network, the Regional office of MCSS, and local community service agency allies who support the development of person directed individualized support.

The CHOICES Project in Thunder Bay unfortunately was not able to keep going. The CHOICES Project was funded in an effort to explore how an individualized funding model could work and what it might look like. One person suggested that perhaps “we were ahead of our time for a period of time and then it just wasn’t time”.

For more than 20 years, the Ministry has invested in “projects” to explore new ideas. However this era of “projects” has led to a start and stop pattern in communities across the province. A good idea begins, but there is no means of supporting the idea past the end of the project.

In the Social Inclusion Act (Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008), the Ministry identified “Person Directed Planning” as a valuable approach for developing individualized support in the community. People can now choose to spend 10%, up to \$2500, of their Passport funding to purchase the services a person directed planner. The intention behind this is to enable people to develop a vision for how they can use the resources available to them.

Over the last 20 years other organizations have formed, or taken on “projects”, to create ways of assisting people to develop individualized, community first, support that focuses on people directing their own lives. However, up until this point, the Ministry has had no vehicle for funding this kind of work.

THE INDEPENDENT FACILITATION DEMONSTRATION PROJECT LAUNCHED

The Independent Facilitation Demonstration Project (IFDP) is a collaboration between the Ministry, OIFN, and 7 Independent Facilitation Organizations. The IFDP was created with three objectives:

- To increase the number of people who are receiving independent facilitation and planning;
- To evaluate the outcomes of independent facilitation and its impact in the lives of people who choose it;
- To build the capacity of grassroots independent facilitation organizations so they are able to retain facilitators and operate sustainably.

The expected outcome of the Project was that approximately 1100 new people would be engaged in Independent Facilitation services across the seven Ontario communities.

To create Independent Facilitation, a core task was to invest time in listening to people and their families locally and in other areas of the province.

The Ontario Independent Facilitation Network (oifn.ca) and seven independent facilitation organizations are working together on this project, which launched in April 2015. The IFDP has been extended for a bridge year and continued until March 31, 2018.

To date the Ministry has not established ongoing infrastructure resources, in particular sustainable funding, The IFDP has been extended for a bridge year and continued until March 31, 2018, with hopes of annualized funding beyond April, 2018.

independent facilitation organizations participating in the IFDP

- **Bridges to Belonging Waterloo Region**
Cameron Dearlove, Executive Director, cdearlove@bridgestobelonging.ca,
519-501-8714
- **Citizen Advocacy Ottawa**
Brian Tardif, Executive Director, btardif@citizenadvocacy.org,
613-761-9522 Ext 225
- **Facile Independent Facilitation**
Diane Peacock, Executive Director, diane@facileperth.ca,
519-271-6565 Ext 200
- **Facilitation Wellington Dufferin**
Joanna Goode, Director, JoannaGoode@facilitationwellingtondufferin.ca,
519-546-1471
- **Families for a Secure Future**
Judith McGill, Executive Director, jmcmill@familiesforasecurefuture.ca,
647-693-9397, 416-997-3311
- **Partners for Planning**
Jeff Dobbin, Executive Director, jdobbin@p4p.ca
416-232-9444
- **Windsor-Essex Brokerage for Personal Support**
Marlyn Shervill, Executive Director, marlyn@webps.ca,
519-966-8094

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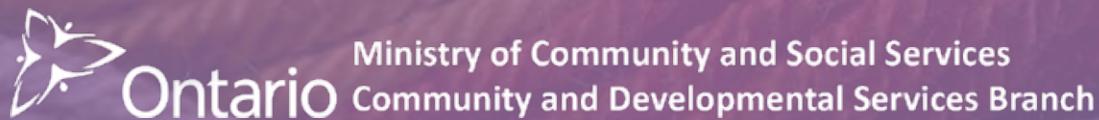
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learning so far...

weaving a story of change

The Independent Facilitation Demonstration Project



Part B:
what people say they want and need

Part B: What People Say They Want and Need

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community gatherings

One part of the IFDP, was to reach out to communities that are not currently served by Independent Facilitation, to explore how they could develop this offering. The IFDP initiative gathered people in six communities to explore how Independent Facilitation could assist adult citizens with developmental disabilities.

People with disabilities, family members, and allies interested in the work and value of Independent Facilitation gathered in:

- Hamilton/Brant (April 2016)
- Kingston and area (April 2016)
- Thunder Bay (May 2016)
- London and area (May 2016)
- York Region (May 2016)
- Huntsville, Parry Sound, and Near North communities (June 2016)

The groups had conversations that explored:

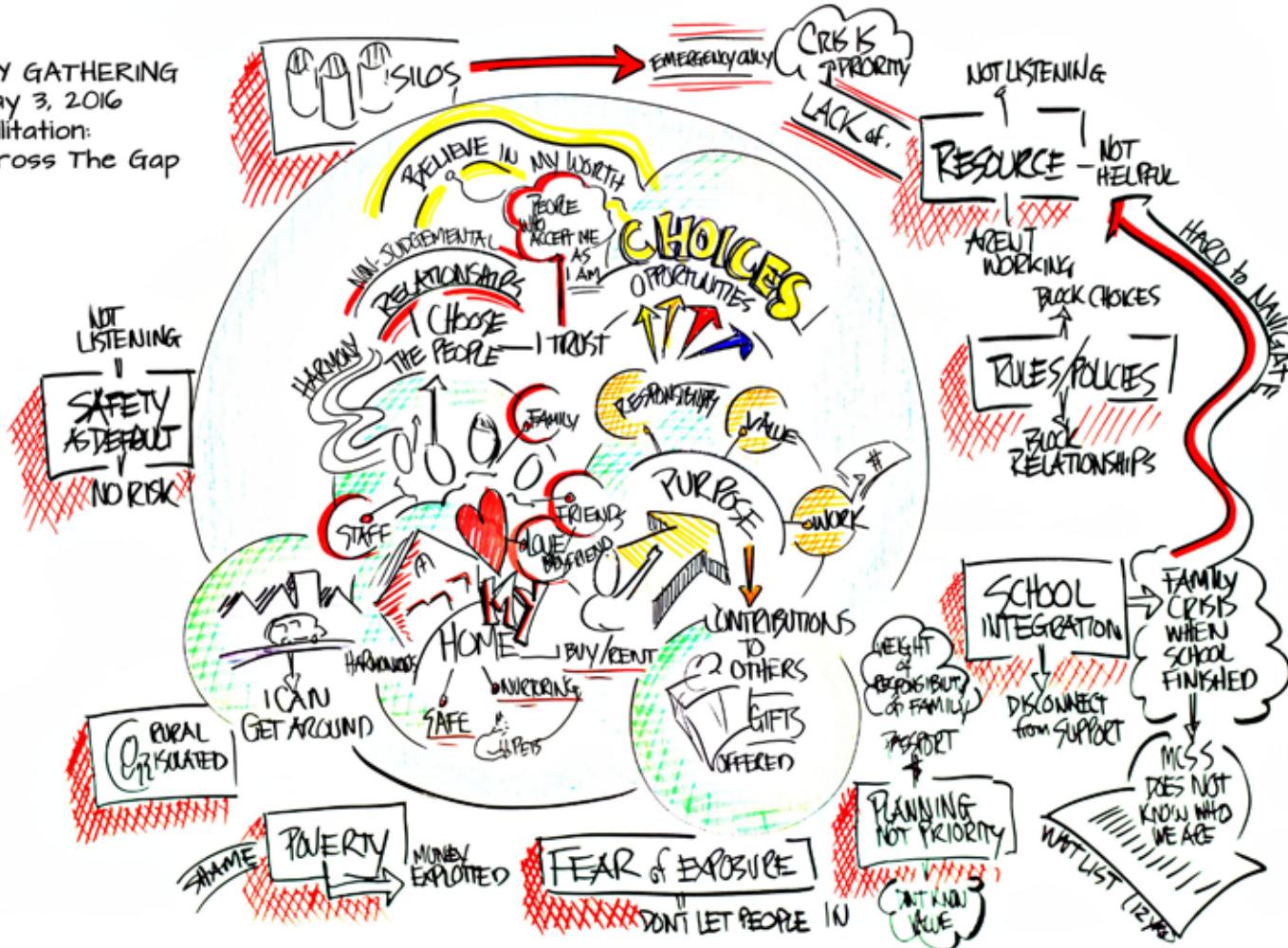
- *What would a good life look like?*
- *What is life like now?*
- *The role of Independent Facilitation in bridging the gap between now and the future people need and want.*

They Summarized their Good Life aspirations into seven topics:

- Home
- Relationships
- Choice & Control
- Purpose
- Work
- Valued Sense of Self
- Money

Separate reports have been developed from each of six (6) Community Gatherings. What follows is a summary of the topics and themes across the six community gatherings. The graphics are examples from 1 of the community gatherings, in Thunder Bay, however the narrative for What would a Good Life look like? and What is life like now? are summaries of what we heard across communities.

OIFN COMMUNITY GATHERING
 Thunder Bay, May 3, 2016
 Independent Facilitation:
 The Journey Across The Gap



what would a good life look like?

HOME

People spoke about having a place to call home; a place that is theirs; where they can feel safe; a place where they are in control; a place where they can choose who they live with, and who they welcome.

For adults with developmental disabilities having their own place to call home is an important sign of growth, moving forward, and becoming a citizen. Home is the base in their community that demonstrates that they are equal. It makes it possible to establish relationships with neighbours, and friends. It is important that home be located in a place where it is possible to get around easily, to get to and from work, to go shopping, to participate in classes, a faith community, activities of interest to them.

For families, a place that is home for their loved one is about preparing for the future now. It is about preparing for the time when they may not be around. Creating home now is about figuring out what it will take for the people they love to be safe, and putting the right support in place. It is about creating space for sons and daughters to grow. It is about making room for their relationship to change as they all age.



RELATIONSHIPS

People want to have friends and grow in the number of their friendships. They want the opportunity to find someone to love, to have intimacy in their life. They want to belong. They want relationships with their family, but they want the relationship to change, to no longer be dependent as they were as a child.



Families want to know that there are other people who love and support their loved one. They want to know that they are not alone. They want to know that if they were no longer around, there would be people who would be there to support and love their loved one, people who would know that they were ok, people who would make sure that they were safe.

People with developmental disabilities want to know that they have people in their life who will stand by them, people who believe in them, who care about their dreams and desires, and want them to succeed.

CHOICE and CONTROL

People want to know they have a wide range of choices in their life that they can explore. They are not looking for the choice between one program “space”, “slot”, “vacancy”, “bed”, or another.

People want to know that they have many options, opportunities to pursue the visions and dreams that they want to work toward. They want to know that they have choices about where they live, and who they live with. If they need support people, they want to be able to choose who will support them; what kind of support that they need; how that support will be provided; and when they need the support during the day and week. They want control over their lives and be able to direct where their life is going.



People want to be able to make choices that allow them to try. They want the chance to take risks, and even fail, so that they can learn.

People want to grow in their ability to make choices, and to learn how to be responsible for the choices they make. They want to know how to use their own power to make things happen in their life.

People and their families need resources and support – which means enough funding and money to be able to make choices.

PURPOSE

People want to have a sense of purpose. They want to know that they make a difference. They want to know that they are valuable, that they bring value to people in their life and the community where they live.

They want the experience of belonging that comes from others recognizing that their presence makes a contribution to the whole.

People want to strive to accomplish goals that they set for themselves.

WORK

People want to work. They want to be paid fairly, and valued for the contribution they can make. They want to earn money to support their lives, and pursue their dreams.

Many people don't just want a "job", they want the opportunity to have a career; to be able to progress beyond the place where they start. They want to increase their skills, and take on more responsibility.



VALUED SENSE OF SELF

People want to feel good about who they are and what they have to offer. They want to have roles where they are recognized for bringing value. They want to see themselves in positive ways.

People want to be heard. They want to know that what they think, say, and do is important. People want to speak up and use their voice to communicate. They want to be taken seriously.

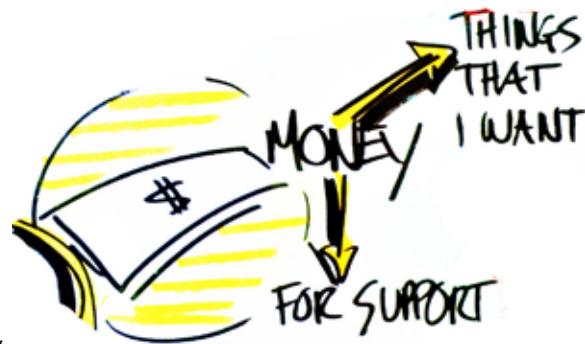
People want to be seen as citizens who have the same rights as all other citizens.

MONEY

People want to break out of poverty and being poor. They want enough money to pursue their hopes and dreams. They want enough money to experience what it means to take care of themselves.

People and their families want enough funding for support so they can move past just "surviving". They want resources that make sure they can be safe, but they want to go beyond just being safe, they want to participate, to be involved in relationships, in community groups, in work. They want enough funding to support them to accomplish the goals they set for themselves.

They want enough money and funding to have a sense of freedom.



what is life like now?

What we heard at the Community Gatherings

It is important to know that the messages shared in this section reflect some common themes heard across communities. In most communities there are, and could be, exceptions to what is said here.

THE GREAT BLACK HOLE WHEN SCHOOL IS OVER

When people with developmental disabilities finish school, it is common for people and their families to experience nowhere to go, and no support to explore possibilities. Families feel alone and confused about how to help their loved one fill the 30-40 hours each week that school used to occupy. People feel trapped in their family home.

THE CONFUSING MAZE WHEN LOOKING FOR SUPPORT

When people and families turn to the government in search of support, they meet a confusing and disconnected maze. Support for finding a place to live is different and separate from how to find work and get engaged in the community. Health and mental health related issues are separate from community support. People feel bounced from one place to another. Each time a bump happens, people and families have to start explaining their situation and request for support all over again. That alone is crazy making.

A HARMFUL NEGATIVE FOCUS

Families expressed how painful it is that the system forces them to see their sons and daughters in the most negative ways. One parent said it was like going to the emergency room. If you were not showing up in crisis, then you would not be a priority. People and their families must focus on all of the negative parts of their lives. They have to appear to be desperate. If people and their families have some resources, but not enough to get past surviving, they are moved down as a lower-priority need for resources.

NOT BEING HEARD

In general people and families do not feel that they are heard. The system as it is designed is not really set up to listen.

For people themselves, so called “experts” and family members are expected to speak for them. Somebody else is expected to be in charge of what happens to them.

MUST FIT INTO SLOTS and VACANCIES...OR WAIT ON A LIST

People and their families feel like the best that they can get when they look for support is a “slot”, “a bed”, “a vacancy”, “a space” in a program. They don’t feel that it matters who they are or what they want and need. They are simply offered what is available even if it is not what they are looking for, or told they would have to go on a waiting list.

Many families are desperate to have some place for their loved one to go, and something to do during the workday in the week. Parents have to work to sustain their family. Many do not want to send their son or daughter to a “space” in a Day Program, or move into a “bed” in a group home, but they feel like they have no other choice.

RELATIONSHIPS...STAGNANT, LOST, ISOLATED, and DEPRESSED

As adults finish school, people find themselves staying at home with nothing to do. As they wait, skills they worked hard to gain, fade. They get lost in doing nothing, watching TV and videos. Many people have no friends to spend time with.

Many families watch as their loved one gets more isolated and depressed, but they don’t know what to do to connect them to new relationships. They get stuck in their relationship with their son or daughter. The relationships at home become stressed. Everyone is lost and frustrated. Time passes and it only gets worse, and harder to get out of the isolation and depression.

COMMUNITY EXPECTATION and LACK of EXPECTATION

Many families experience the attitudes and prejudice of extended family, neighbours, and general community relationships. Families often find that other people believe that there is “a special place” or “program” for their loved one. This leaves people and their families feeling isolated. They struggle to communicate that they are not looking for a program, or that there aren’t any available. In general families face a social view that other people in the community believe that “someone else is taking care of their issues”.

RULES, POLICIES, and PRACTICES THAT GET IN THE WAY

Many people and families feel that the DSO has become a “gatekeeper” between them and organizations that they would want to talk about finding solutions.

People and families have experienced the DSO system has preventing people from connecting with Service Agencies directly. Confidentiality regulations prevent the DSO from providing a simple powerful support by linking people and their families with other people and families who would often be able to support each other, share knowledge and experiences with one another.

In the education system, the same pattern of blocking access to links with families who could support each other persists, all in the name of confidentiality.

People and their families find that available programs are designed to block relationships from developing. Agencies have not developed the necessary knowledge, skills, practices, and resources to support people in developing relationships beyond the program.

Programs are organized to be self-contained safe places, protecting people from relationships in the community. The system is built upon fear of abuse from “strangers”.

The group nature of programs limits the choices available to any individual person. There are not enough staffing resources for people to pursue their interests, connections and potential relationships.

POVERTY and LACK OF SUPPORT FUNDING

By design, individual people with developmental disabilities are poor, and are kept poor by income assistance programs like ODSP.

Poverty limits choices. Low income, the lack of affordable housing, and accessible available transportation cut off the choices to people. People become dependent on the decisions and availability of other people (family members, and direct support staff in particular). People do not feel free to explore their own lives.

It was not uncommon to hear families speak of parents having to quit jobs and careers when their loved one finished school, so that they could be available to support their sons and daughters. This reality adds additional hardship and stress that just continues to grow. Relationships within their household are stretched to breaking points. There are additional hidden costs with this kind of enforced poverty. There are substantial increases in emergency health care, diminished purchasing power (think groceries), and in the long term, poverty in retirement.

Families with low incomes feel a fear of their financial circumstances being exposed, and then judged or put under increased observation. They feel shamed by the system they must turn to for support.

Many people have very limited, or no funding for support available to them.

Some families feel forced to pool resources with other families, creating group supports that ultimately limit the individual choices of people. These families are not looking for a group program, they simply feel they have no options available to them, and must have a place for their loved one to go.

PLANNING IS NOT A PRIORITY

Most families expressed how dramatically the world changes when their loved one completes school. They speak about being “tossed over a cliff”, or “falling into a black hole” where they are alone. People and families did not feel that anything had prepared them for this experience.

School transition planning was either non-existent or simply not useful. There was no connection between the support received while in school, and the support they would require when they leave school.

LACK OF RESOURCES...north and rural

All of the challenges and realities listed above are simply magnified for people who live in rural or northern communities.

“nowhere to turn”

The Ontario Ombudsman Report

In August 2016, the Ontario Ombudsman delivered a report on how the Ministry’s resources are used to respond to situations of crisis involving adults with developmental disabilities. The Ombudsman identified several issues and problems that plague the Ministry. The heart of these concerns are:

- Inappropriate places to live, including long term care, hospitalization, and incarceration
- The need to find better ways to support people with complex needs, too many of whom are in crisis or at risk of homelessness
- The service system is difficult to navigate, including lack of co-ordination for people with complex needs, and inconsistent case management

The title of the report says a lot — “Nowhere to Turn”. The Report identifies that by the time someone finds themselves in crisis, there is no clear place to turn to figure out how to deal with difficult, painful, and even dangerous circumstances.

Our conversations in communities across the province would indicate that people are not really looking for “someplace” to turn.

They are not interested in a phone number to call that refers them to someplace else, or more than one other place.

They are not interested in just getting information about what they can do.

They are looking for a real person, “SOMEONE to turn to”; someone who will be with them, listen to them to understand what they really need, and what they are looking for; someone who not only helps them find the information, people, and resources necessary, but helps them figure out what to do with this knowledge and these resources.

They are looking for someone to stay with them through the crisis, and after the crisis when they can focus on the life and support they really need and want to be healthy, safe, and connected as a community member.

Ideally they are looking for someone to turn to before they are in a crisis; someone who helps them think about what they need to avoid a crisis; someone who helps them find community solutions and connections that prevent them from needing expensive “placements” that do not address the root causes of crisis.

independent facilitators — “SOMEONE TO TURN TO”

The core of being an Independent Facilitator is as “someone to turn to”; someone who will walk with a person, and their family, as they try to figure out together how they can live the life they want to live, with the support they need that can work for them.

An Independent Facilitator is someone who enters into an ongoing relationship with a person, and those who love them, meeting people where they are at, listening deeply, and assisting them to find a way to bridge the gap between where they are now and where they need and want to be, as a member of the community where they live and work.

You can read more about the work of an Independent Facilitator in Part C: What Is Independent Facilitation and Who Can Benefit.

Part B: references

Hamilton and Niagara Region Community Gathering

(2016) OIFN, Independent Facilitation Demonstration Project

Kingston and Area Community Gathering (2016) OIFN,

Independent Facilitation Demonstration Project

Thunder Bay Community Gathering (2016) OIFN,

Independent Facilitation Demonstration Project

London and Area Community Gathering (2016) OIFN,

Independent Facilitation Demonstration Project

York Region Community Gathering (2016) OIFN,

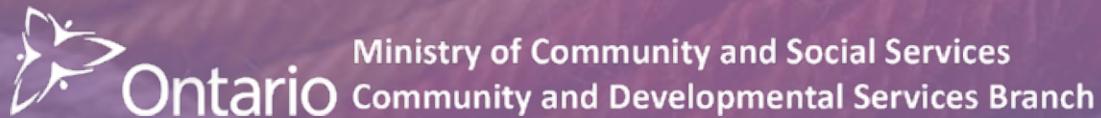
Independent Facilitation Demonstration Project

Near North Community Gathering (2016) OIFN,

Independent Facilitation Demonstration Project

weaving a story of change

The Independent Facilitation Demonstration Project



Part C:
what is independent facilitation and who can benefit

learning so far...

ontario
independent
facilitation
network
oifn.ca



Part C: what is independent facilitation...and who can benefit

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what is the purpose of independent facilitation?

The purpose of Independent Facilitation is to make it easier for:

**people with disabilities to direct their own lives,
live as valued citizens,
and find the support they need
to take their place as community members.**

Words can mean different things in different circumstances. For our purposes, here are some meanings for words and phrases that we use in this document.

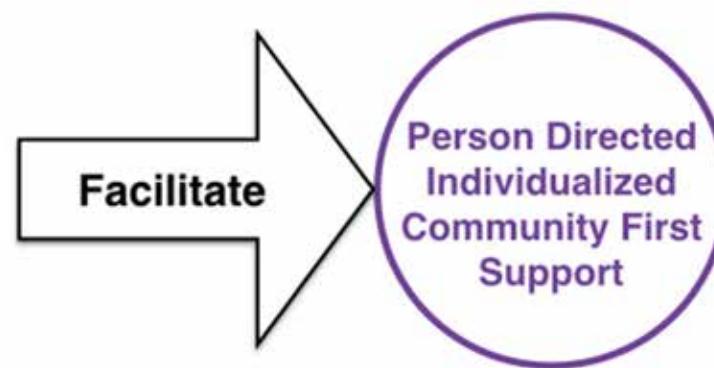
person directed individualized community first support

The word **FACILITATE** means “to make easy”. In this case it means that a FACILITATOR works to make it easier for people with developmental disabilities, and the people who love them, to:

- Be **PERSON DIRECTED** —People want and need to DIRECT their own lives. For people to live as CITIZENS they need to discover how they want to live and what they need to do that.
- **INDIVIDUALIZED** - People are looking for support that works for them, and the people they love. This means identifying the right kind of support; the right people to provide support, in the right way—the way people need and want it to be done; and at the right time—when people need it, so that they can participate as citizens and valued community members.
- **COMMUNITY FIRST** means focusing on discovering the people, relationships, places, and resources within the community, that can make it possible for people to establish relationships and contribute to people and places that are important to them. Community First also means working to limit the need for services, that so often make life complicated and limit the freedoms of the people receiving the services.

- **SUPPORT** is provided in a way that builds a foundation for people to live as citizen. Support focuses on strengthening people's capacity and power to direct their own life and grow in responsibility for themselves; the decisions they make; and the relationships they choose.

what does “independent” mean?



INDEPENDENT means that a Facilitator works outside of an agency that provides direct services for people with developmental disabilities. It means that they are not directed or controlled by the management of a service agency, or how the agency is organized to do business. It means that they are unencumbered by the services agencies provide, and can look beyond the way things have always been done.

An Independent Facilitator *works for the person*. People, with the support of those who they love and trust, are the Directors. Facilitators are guided by the vision and goals of the person. Facilitators are accountable to people, and their families.

stories that can help us see the work

Throughout this section we will share some experiences of people who have been supported by an Independent Facilitator. We share these stories to help shine a light on the nature of the relationship and work of an Independent Facilitator. Here is a brief introduction to people and where they were at when they met the person who would work for them as an Independent Facilitator:

larry

Larry is a 38 year old man. Larry has cerebral palsy and is quadriplegic, unable to control the use of his arms and legs. He uses a wheelchair and requires physical support and care to get by everyday. He was living at home with his Mom, when she got very ill, and had to go into the hospital. Larry's Mom was the primary person providing support and care. When she went to the hospital, Larry was not able to stay at home on his own. He was placed in a nursing home, surrounded by many people who were in the last stages of life. It was clear that he did not belong, but there was nowhere else to go. He has a solid relationship with his Mom, and both of them were very clear that Larry could live in his own place in the community. They just did not know how to get there. He had been living in the nursing home for 18 months when he met Trudy, his Independent Facilitator.

john

John is a 37 year old man. He says he was misdiagnosed, and as a result never got the support that he really needed. "I was spiraling out of control by doing a lot of drugs and alcohol, I was homeless, and even put in jail. I had my parents really scared and I couldn't function. I was scared too." He was living with his parents, not because he wanted to, but he had no other options. John had no access to funding or services. He says he was "on all kinds of waiting lists and waiting for funding". In the past, he had not had much success with services. John was not sure that he could expect anything from an Independent Facilitator.

morgana

Morgana is a 31 year old woman who loves people and thrives in social situations. She lives at home with her Mom and Dad in a rural community. Morgana's Mom has a full time job, and her Dad works full time running a small business. Morgana was born with Spina Bifida and has some paralysis that affects her legs, fine motor movement in her arms and hands, and some of her internal organs. As a result Morgana has medical complications that require ongoing attention and care. During transition, the school helped Mom connect with CCAC for health related needs. Morgana and her parents received SSAH funding that eventually became Passport, enabling them to hire support workers to assist Morgana in getting out into the community. In the 10 years since Morgana completed her school experience, Mom and Dad have coordinated and managed 2 funding sources (Health and MCSS), health care staff and community support workers (many people in and out of their home), and all of the ongoing health issues that arise in Morgana's life, including one incident of pneumonia that almost killed Morgana. By the time they all met the Independent Facilitator, Mom and Dad were exhausted and stressed out.

beth

Beth is a 23 year old woman who lives with her parents on the family's working farm. Beth is a very capable woman, who contributes in many ways to the work of the farm, cooking meals, assisting with the birthing of the lambs, and other chores that need to be taken on. Beth's family is rooted in longstanding traditional roles for men and women within the family that have made their farm work for a long time. When Beth completed school, she had nowhere to go. She was lost without a clear role. She wasn't one of the men in her family who worked in the barn and fields, and she was not getting married, raising children, and homemaking. She was isolated in a rural setting far from a town with no way to get around on her own. Beth became very depressed, frustrated and angry. She alternated between being withdrawn and silent, and lashing out in anger. Her self esteem was extremely low. Her relationships with her parents were stressed and growing in conflict. Beth was using the internet to look for relationships with men, and was engaging in risky behaviour, connecting in person with men she had never met before. Beth was not in a good place, and her family was stressed and at a loss as to what to do. While Beth had support from a local Community Living agency for a few hours a month, it really did not meet Beth's needs.

lily

Lily is a 22 year old woman. She is enthusiastic, capable, and filled with energy. She needs and wants to be active and moving. Like many people, when she completed school, she had nowhere to go, no job, and no way to get around on her own. She was living at home with her Mom in a rural area. In many ways she was stuck at home. Lily's Mom needed to keep her job. In addition, she was struggling with her own health related issues. Lily's high energy had no outlet. She didn't have enough places to go. It was all creating high stress that was overwhelming her Mom. Lily attended a day program for 2 days a week, but only because she had nowhere to go. Her aunts noticed that Lily, and her Mom's situation was getting worse day by day. They were concerned for both of them. Something needed to be done, but they were lost as to what they could do. Lily's aunt reached out for support from an Independent Facilitator.

the work...

In general, the work of an Independent Facilitator is to pay attention to one person; be “someone to turn to” for a person with a developmental disability— someone beyond family; someone who is not working for a direct service agency, someone who is independent, and not directed by the interests of other authorities.

An Independent Facilitator is someone who works to do whatever it takes to make it easier for people with developmental disabilities to grow in their ability and power to direct their own lives and customize the support they need to live and participate as a citizen and community member.

While it is true Independent Facilitators work for the person and are directed by the person’s vision and goals, the focus of the work is “person directed, individualized, community first support”. If you are interested in a “safe group program”, “a nursing home”, “a day program” that is self contained, Independent Facilitation is not likely to be for you.

An Individual Focus...supports that are provided with an individual focus are flexible, responsive to individual needs, and provide persons with disabilities with maximum control over their provision.

In Unison (2000)
Federal, Provincial,
and Territorial Ministers
Responsible for Social Services

five main areas of work for facilitators

We have learned that there are 5 main areas of work for Facilitators (see below.). These areas of work require different knowledge and skills that a Facilitator must develop, but they are not separate. Each of these aspects of the work is connected and interdependent with all of the other aspects:



relationships

Being in relationship with other people is the most important thing about being human. We survive by being in relationships where we give to, and receive from, each other. We are safer, more likely to be healthy, and live longer if we are in relationship with people who freely choose to be in relationship...friends, lovers, families, neighbours, etc.



RELATIONSHIP WITH SELF

...growing in trust and confidence

In the world of developmental disability, there is a history of low expectation, or no expectation; of paying attention to what is wrong with people; of expectations that “there is a place that will take care of people”; that people cannot and will not be in charge of their own lives. The end result is that many people have never had the opportunity to develop the skills to be in charge of their lives; to be connected in reciprocal relationships with friends, partners, mates, allies.

The most devastating result is that many people come to believe that they are not valuable enough to be in relationship, that they have nothing to offer, and they are not capable of directing their own lives.

A Facilitator’s primary working relationship is with the adult citizen with a disability. In the beginning it requires listening deeply to discover who somebody is, what are their gifts, and capacities, their strength of character, their vision, how can they make a difference, and what support will they need to do this.

The Facilitator holds the belief in people as valuable. The Facilitator brings a curiosity without judgment, looking for the gifts and value that people possess.

John says it well...

"When I first met Barb, the Independent Facilitator, I was skeptical because of the fact that I have met service providers before who just sat there and patronized me. You know you can tell when that happens. But Barb was a breath of fresh air. Barb proved to me that she was different, just by smiling, shaking my hand and I sensed a difference. It was the first for me in a long time.

Right away we got to work by talking about what I wanted to do and what would be a first things to start with. Within a very short period of time, I was volunteering at the Local Food Co-Op, connected with an employment service, explored the local music scene and I got a part-time job at No Frills. She really listened to me and acted on what she said she would look into. She introduced me to things I didn't think were possible and I trusted her. Finally, this was a person who really cared about me and cared about where I wanted to go, and she was fast! She made me do my homework and got me calling around too. Barb got me talking about the possibility that I might move out and have a roommate and even have money left in my pocket. I thought if she believed in me, then I should too."

People need someone to listen. They need someone who can take the time to understand what they have to say, and the way that they express it. Facilitators meet and listen to discover what the person thinks, how they think, and how they communicate what is important to them.

A Facilitator begins with a belief in the value of each person; a belief that they have gifts, strengths, capacities; a belief that ultimately they know what is important to them. Together they begin a relationship as a journey to discover and uncover these things.

It takes time for many people with disabilities to trust that someone is genuinely interested in what they think. Many people find it hard to believe that someone is actually interested in what is important to them, and what they would like to see change in their life. Trust is built by listening without judgment. Trust is also built by follow through, by doing what you say you will do.

When Beth and her parents first met Judy, the Independent Facilitator, she was quiet. She sat with her head looking down. She didn't want to talk. At times she would just lay her head on the table and not look up. Her relationship with her parents had become strained, and when her parents spoke, Beth would become angry.

It became painfully clear that Beth was not getting along with her family. She did not want to talk about it. Her parents just wanted things to be different. It was just too hard for everyone. When the first conversation came to a close, Judy gave Beth her business card and asked her to think about what she wants, and if Beth would like to work with her to give her a call.

Beth did call. She asked if she could meet Judy without her family. Beth began meeting with Judy on her own. She began to talk, and express what she was feeling. She was able to talk about feeling lonely; about how difficult it was to live on a remote farm with no way to get around on her own; about how she did not feel she had a role and purpose; about not knowing where she fit in her family.

Beth was able to talk about how she had a history of starting something and then quitting —going to the gym, or volunteering, etc.. She talked about not really knowing what she wanted. She couldn't talk about goals, or things she wanted to accomplish. Throughout the first year, her facilitator would help her make a connection in the community, but it would not last. Beth would start,

and then lose interest.

Beth was able to speak about how she did not feel confident, she would say “I wish I did not have a disability”. Judy was someone who would listen, without judging her, and help her to think about small things she could do to address what she was feeling. For almost a year Judy became a person Beth could turn to, as she made her way through her low self esteem, gradually gaining some confidence as she grew to trust Judy, and more importantly, trust herself.

Some people are very clear about what is important, their belief in themselves, and the change they want to create.

Trudy, an Independent Facilitator met Larry at the Nursing Home where Larry was placed. Larry shared that he was on every possible waiting list for group living in the region.

Trudy asked the question, “What are you waiting for? Where would you really want to live and what would that look like?” Larry believed that he could live in the community, and so did his mother. Larry was also clear in expressing what was important in his life.

Larry expressed an interest in moving to the town where he had lots of natural supports; his sister, her husband, and nieces; his father and his wife and children; and his biggest supporter, Mom, who lived 30 minutes away. At the same time, Larry was very clear that he wasn’t about to settle and end up back in a nursing home. He wanted assurances that he had enough support to be successful so he could have a life again.

When people are clear about what is important, and the change that they want and need to create, this focuses the work of the Independent Facilitator to keep doing things that make it easier and more possible for people to move in the direction of their vision.

RELATIONSHIPS WITH FAMILY

As adults, people often find themselves stuck in their family home, with nowhere to go and nothing to do. The world changes dramatically when school is no longer a place to go for 30-40 hours each week.

By the time their son or daughter, brother or sister, reach the age of 21 parents and families are exhausted. It is not hard to understand how families have come to believe the negative things they have been told about their loved one, and their experience has reinforced.

The idea of people being able to direct their lives can seem impossible for many families. It is not that they don't want see that possibility. It is that finding support has been so complicated, confusing, and frustrating for them. They have a hard time imagining that it would be possible for their loved one to do it when they find it so difficult themselves. Families have experienced that they are the ones left having to deal with things when they don't work out, and they don't work out often.

Facilitators listen to what family members think, how they think, and how they communicate what is important to them.

Facilitators listen for the differences, and the similarities between what the person with a disability thinks is important, and what their family thinks is important. Facilitators listen without judgment.

A significant part of the work of Independent Facilitation is supporting the vision of the person, and supporting the person with their family as they become clearer about what is important, **and what they want to change**.

Just as a Facilitator holds a belief in the person, their value, gifts, and capacity to contribute, a Facilitator holds a vision of a "win/win" outcome for the person and their family.

Supporting family, and particularly the work that they do to support their loved one is a critical part of the work.

Morgana's Facilitator, Linda, had been spending time with Morgana, finding out about who she is, her interests, and what was important to her. Together they identified setting up her own business, and possibilities for cooking classes. They prepared a chart with Morgana's ideas about what she wanted to do. They shared it with Morgana's Mom. Mom listened, but at one point she became very emotional, "I am exhausted. I just don't have the stamina any more." She was thinking about all of the work that she would have to do with so few resources to do it.

Linda stopped. She turned to Mom and said, "What do you need?" .

Linda was able to listen to all the things that had already been tried, all of the complications and dead ends they had reached: Morgana had been on a waiting list for housing since she was 16 years old; local service agencies could not accommodate Morgana's medical needs in their residential options; they were told that the only place Morgana could go was a nursing home. Mom did not want a nursing home for Morgana, or even a group home, but she was becoming desperate. Two years ago, Morgana's Dad had a heart attack that scared them all. Mom and Dad "needed to know that Morgana would be OK if anything happened to us."

In addition to Morgana's interests in small business, cooking, and other community engagements, finding a place to live where she could be supported, became a top priority for Linda and the work she would do together with Morgana and her parents.

Sometimes a Facilitator can create the opportunity for families to have new conversations together in new ways.

Nora, the Facilitator, met with Mom and Lily every week for about 6 weeks to explore gifts, interests, likes, dislikes and new things Lily wanted to try. They made several lists and then each meeting would have Lily tell them what she wanted. Although Mom had been having her own challenges related to her health and energy, both she and Lily felt supported and they could see relationships were building.

The role of a Facilitator becomes clearer as their relationship grows with the person and their family.

Larry's mother, shares, "As a parent, I just don't have the connections, know who to call, or what doors to knock on." Fortunately for their family, their facilitator Trudy had the energy, the connections, and skills to create a positive nine month transition process.

FRIENDSHIPS

It is not uncommon to find out that many people have no friends, or no way to stay connected to friends. Nobody can make friends for other people, but Facilitators can work to set up the possibility for friendship to develop.

By learning more about the person, their interests, their gifts, their passions, and their goals, a Facilitator can help make connections to places, and people that can grow friendship.

A Facilitator can support people to find ways that they can show up in the community, where they feel good about themselves. The other side of the work is knowing places and people that they can introduce and connect people to.

Beth's confidence grew over the first year with Judy, her Facilitator. Gradually she started to commit to experiences that Judy helped to connect her to. She got a job at a local restaurant. She found a counselor that she liked who could support her over the phone. She joined a local drama group, working on sets and props. She began going to a local dance group that got together every few months. As she felt better about herself, she started to form relationships. She made friends at work, with people who were her own age, and had much in common. One person at work has become a very close friend. She made friends at the drama group. And she started dating a man she met at the dance group. She is actively connecting with her friends through social networking on her computer. Judy helps her to think through how she can keep these connections and friendships going, working out ways that she can get transportation, sometimes arranging for a ride with people who are participating in the things she is involved in, and prioritizing the things she needs to ask her Mom's support to drive her places,

RELATIONSHIPS WITH SYSTEMS

Shurlan speaks about his experience with services and systems:

**"People act like they care, but they really don't.
They just want their money."**

A common theme that we hear from people and their families is that connecting with "systems" is exhausting, confusing, and frustrating. The main reason for this is that these systems are neither person centered, nor person directed. People and families feel like who they are, and what they need and want, is just not important. When people have to meet "systems", they discover that programs, policies, rules, liability, and money are what is important.

People often find themselves having to face multiple systems: the Ministry (MCSS) for funding, services, and ODSP; the Ministry of Health for medical and/or mental health; the Corrections system; the police; the Courts system; Housing authorities. One system is overwhelming. Multiple systems is mind boggling.

Facing these alone feels like torture. Facilitators often work to "make it easier" for people to make their way through the confusing maze of systems. They walk with people, supporting them to hold their vision and what they need as the things that should drive the use of government resources.

While Larry was living in the nursing home, he was on a waiting list for 24 hour support. There was nothing available. His Facilitator, Trudy, helped him get clear about where he wanted to be, and what he wanted his life to look like. He wanted to live in his own place in the town where his family and extended family lived.

Trudy started connecting with agencies she was familiar with in town. She found out that one organization may have some Supported Independent Living (SIL) resources available. This kind of support could be provided in Larry's home. SIL staffing resources are provided through MCSS, and this meant that they could only be accessed through the

DSO. Trudy contacted the DSO to explain the situation, and the DSO was willing to consider this, but the 30 hours per week that could be available would not provide enough support for Larry who has total physical care needs.

Trudy supported Larry and his Mom in making connections with the local CCAC (Community Care Access Centre operated by the Ministry of Health). Together they went to several meetings with the CCAC presenting the need for maximum supports.

The CCAC contacted a local agency that provided subsidized housing with health and attendant care support. Eventually, Larry, his Mom, Trudy, attended a series of meetings with people from the CCAC, a local Developmental Service agency, and the agency offering subsidized housing with attendant care support.

Finally, a plan was developed that engaged agencies using MCSS funding, and another using Health funding. Larry was able to move into his own home, with support from two agencies and two Ministries.

To this day, Trudy plans with Larry for meetings that include both services to make sure that Larry's customized, quality supports continue.

Shurlan's Facilitator, Joanne, captures some of the role a Facilitator can play when people and their families have to meet different systems, agencies, and individuals:

"Part of this work is partnering with other agencies and individuals that are involved with Shurlan and his family. It can be Community Mental Health, hospitals, service agencies, the Courts, and Legal Aid..."

I find that not all of the people know what the other people are doing. So in that sense, in one way I have a good picture of that, and it actually helps clarify for others as well. They are telling me that, "Oh I didn't know that part was happening..." So it has been a clarifying exercise, and also a really delicate partnering tight rope to walk along. Just being careful about how to interact with different parts of the equation. It has been challenging.

One of the interesting things when I am trying to interact with another individual who is working with Shurlan and his family is that they are always wondering, "well what are you? who are you?". When I explain that I am an Independent Facilitator, they are like, "what's that?". It's an opportunity to explain how we are different...we are not crisis services, in for a short time and then they move on. We are still going to be around after the crisis is over.

Often I know information about how Shurlan communicates for example. Other people may not have tried to listen to what he has to say, or misunderstand his speech, so I am able to translate because I do have a longer history than some people who are trying to support him, or his family through the crisis.

The role of being there consistently allows me to have advantage that is different than just a snapshot from these different points of view."

As people get older there is more chance that they will have to engage with other systems. In so many ways life for people and their families already requires extraordinary effort to deal with poverty, lack of housing, unemployment, depression and other mental health issues that arise from exclusion and isolation. People and their families need support and allies to be with them as they have to face systems that are not person centered.

develop a personal support network

While the role of an Independent Facilitator is to be “someone to turn to” for people, the ultimate vision is that each person has a network of people they can turn to, people they are in relationship with beyond the services that support them.

In a world that has a systemic prejudice against people with developmental disabilities, and is built upon social exclusion, none of us can survive alone. The saying, “it takes a village...” is true.. A significant role for Facilitators is helping people identify “their people”, and gather them together to think, plan, act, learn, and celebrate.

The first meeting with the independent facilitator was held at Mom and Lily's house in a small town in rural Ontario. Included in the first meeting was: Lily, Mom, Grandma and two aunts. Lily has an amazing support circle. The family recognized that Lily needed to keep busy and have ways for her to use her tremendous energy; they wanted a place for Lily to live and a place for Lily to have activities to keep her busy. She was involved in a day program a couple of times a week. She had just started volunteering 1 day a week through her aunt's connection in the community.

Lily really wanted to work. She loved to mow lawns because she loved to be outside. Lily liked to be outside because “she felt free”. Lily had experienced some employment programs in the past however they really didn't work for her. When the support circle met we talked about “is there anyone we know that could offer Lily a chance to mow lawns”? Within a month the support circle had met again and one of Lily's aunts had run into an



"We must see our shared life journey as one of transforming human suffering by creating the supportive relationships we all need to sustain life and of celebrating together life's joys, victories and surprises."

The Power of Vulnerability
Judith Snow

acquaintance who had a landscaping company. She asked about Lily working a couple days a week. He agreed and Lily had her first job and it was outside! – no program, no employment coach. Since Lily had a job 2 days a week and volunteered one day a week she reduced her time at the day program to a half day. Everyone started to see that Lily had many gifts and abilities. She started being more independent in her volunteer role. She also started doing more things in her community – she used her amazing energy to take an urban poling class through the local Parks and Recreation department. She also took on more daily tasks at home. Lily has been very successful.

Once some of the ideas were put in place we started meeting on a monthly basis. We started talking about housing options where Lily could live more independently. Originally the family thought Lily needed to live in a group home. Lily's motto: "I want to be free". When we focused on what Lily was telling us the family recognized a group home would not be the place for Lily. In the meantime Lily and Mom talked about wanting to move to Windsor to be closer to their support circle and also where there was public transportation. This move recently happened. Lily continued with her volunteer role and while she was waiting for her job to start up again in the spring she returned to the day program for a couple of days a week. At the last circle meeting we brainstormed new ideas now that Lily is living in Windsor and there are so many more community options available to her. Grandma noticed Lily didn't seem as happy at the day program. The circle asked Lily about this and Lily said, "I just want to be free". As a result her circle supported Lily to change her schedule to go to the day program once a week. Lily will be returning to her job in May. She will also be exploring other things to do to keep busy. Lily has learned to take the bus to get around.

"One thought that comes to mind significant in our family is the support

and relief that Lily's mom feels because of the guidance you gave us. Her ability to cope and physical health is much stronger." There is still lots more work to do to find the living arrangement that will work best. Lily has already stated she wants to live with a friend.

The person, with the support of their trusted people, become the point of accountability for the Independent Facilitator.

Early on in the process, a network of people who cared about Larry met on a regular basis to plan, to clarify, and to listen to what Larry wanted and needed to move out of the nursing home. He was very sad and discouraged that he was stuck there. The network was very helpful in informing the facilitator what her role was in searching out new possibilities. Larry shares "I was looking forward to each meeting and what I had to do to speed up the process" and noting he felt, "... more hopeful some days and some days I was feeling like I was going around in circles."

Larry's circle continues to meet on a regular basis which includes the network that has been there all along the way.

This personal network becomes the group of people who can work together to create change. They are people who can celebrate success and accomplishment together, and rally around when life's challenges, crises, and losses show up.

community discovery and connection

People want to be citizens, and community members, but mostly they want to feel that they belong. For too long the protective world of services has kept people in relationship with people within services. For people and families who have not been immersed in services and programs, there has been no support to bridge the gap from isolation to participation and engagement as a member of the community. Independent Facilitators work to bridge that gap.



For this to happen Facilitators need at least two things:

- to be unafraid to meet strangers in the community and find out who people are, what they offer, what they need, and more; and
- to be willing and able to introduce people they work for to people in the community, matching people's gifts, interests, needs, and offers, with the right people and places in the community. There is a bit of a matchmaking skill that is required.

"One thing that Barb, and the other Facilitators she works with, are good at is knowing people. I have lived here for a long time but they know people like nobody's business. When my first Facilitator, Barb had to leave the work, I was introduced to Mary, a new facilitator. Well she was terrific too. Mary introduced me to Dennis who lives in our town with his wife Diane and Ron who lives in their basement. We started hanging out. Mostly going for breakfast, drives, chilling and talking. When I get depressed, I get so sad that I can't figure out how to get out of it. I soon realized that Dennis had a heart of a lion."

Sometimes it is even better to find the right person to make the connection and introduction.

When the support circle met we talked about “is there anyone we know that could offer Lily a chance to mow lawns”? Within a month the support circle had met again and one of Lily’s aunts had run into an acquaintance who had a landscaping company. She asked about Lily working a couple days a week. He agreed and Lily had her first job and it was outside! – no program, no employment coach.

Working with people to make connections is important. Sometimes Facilitators make the initial contact and introduction; sometimes they do it together with the people they work for; and sometimes they support people to do things on their own.

Beth and her Facilitator, Judy, identified a lot of interests. Beth wanted to get a job. She wanted to get involved with Drama. She wanted to reconnect with a group that gets together every few once to dance.

Judy helped her to identify places where she might work. They found a local restaurant that needed some help in the kitchen. Judy helped Beth think about preparing for the interview.

They went together to meet with a local Drama group. The people they spoke with identified that there was not any room for Beth as a performer, but she could join the group and help out with the props and sets. Judy helped Beth make a connection with someone in the group who could pick her up to go to rehearsals and performances,

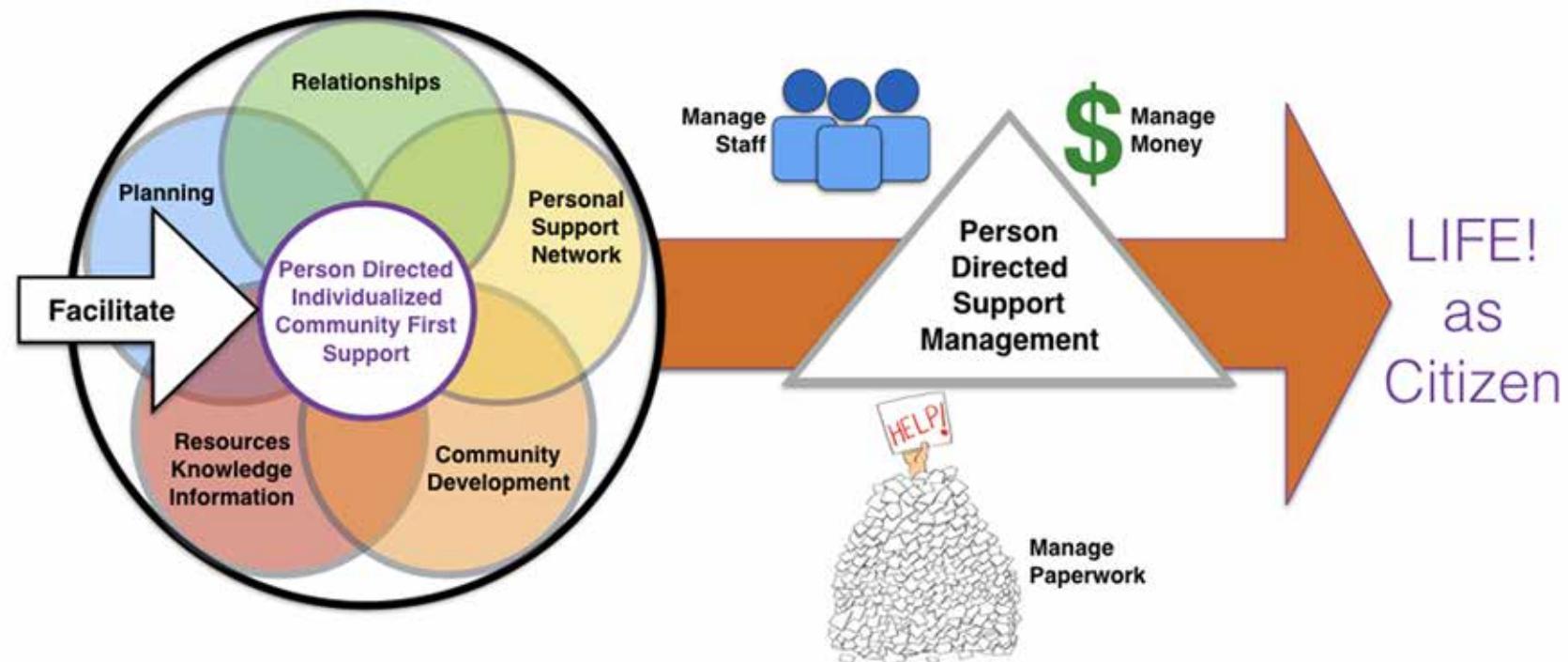
Beth was already familiar with the dance group, so Judy just helped her to sort a way that she could get to the dances.

Sometimes it is important for a Facilitator to be aware of supports and services in the community that can offer support in a way that is in line with the person directed individualized, community first vision and goals of the person they work for.

information, knowledge, and resources

A key component of the work of Facilitation is supporting people in developing their own power and ability to make decisions, and act on them. Families and personal support networks play a critical role in supporting this. People, with their families and support networks, need good clear information, and knowledge about how to use this information, to access resources that can support their vision and needs.

Sometimes the information is about people, places, and organizations in the community that match the person's interest and goals, like Beth in the previous section. Information about jobs, classes, volunteer opportunities, social groups, events. Facilitators assist people in finding this information, and coach them on how to use this information now and in the future, always looking to support people in developing their own capacity to do things on their own, or with their support network.



But there is also a need for information related to resources specifically intended to support people with developmental disabilities, or health related issues, or issues related to poverty.

When it comes to these resources, people and their families have expressed that they do not have a way of getting good clear, and plain language information. When they do get information, it is not clear how to use it, or who can really help them get what they are looking for.

On the left side of the image on the previous page, you can see the scope of the work for Independent Facilitators. The focus is on strengthening people, their families, and allies, making it possible for them to envision and develop person directed, individualized, community first, support that can work for them.

On the right hand side you can see work that is involved with accessing and then managing resources that can be used to create this support. Above the large arrow on the right are the assets and resources of money, staff, and home. Below the arrow is the cost of using those assets —loads of paper work, and rules that must be followed. Nothing is free. Each time people attempt to access assets and resources from government, there are applications and paperwork to fill out, and rules about using the resources that must be read.

Facilitators assist people with learning about what is available —funding, housing, staffing —and what they would have to do to access these resources. They do whatever is necessary to walk people through the process. They provide information, help them interpret what it all means. They may even accompany people to meetings.

Trudy (Facilitator) supported Larry and his Mom in making connections with the CCAC (Community Care Access Centre operated by the Ministry of Health). Together they went to several meetings with the CCAC presenting the need for maximum supports.

*Knowledge is power.
Information is liberating.*

*Education is the
premise of progress,
in every society,
in every family.*

Kofi Annan

The CCAC contacted a local agency that provided subsidized housing with health and attendant care support. Eventually, Larry, his Mom, and Trudy, attended a series of meetings with people from the CCAC, a local Developmental Service agency, and the agency offering subsidized housing with attendant care support.

Facilitators coach people.

When Morgana's Mom was overwhelmed and needed to figure out how Morgana could find another place to live, Linda (Facilitator), began looking for organizations that might be able to support Morgana in the way she needed to be supported. Morgana had never been away from home and her parents, so Linda found an agency that offered temporary respite that could support Morgana's health and physical care needs. The intent was to see how Morgana and her parents would feel about her being away from home. It was an opportunity to learn.

Morgana loved it. She loved the people she met there. For a few months Morgana would go there on "holiday" for a week every month. Morgana got to stretch beyond her family home, and her Mom and Dad got a rest.

During that time, Linda supported Morgana and her Mom in conversation with the organization providing the monthly "holiday". Linda had done some research and found that there could be a possibility of Morgana moving into a house with a housemate that also needed some health and physical care needs. It would mean working closely with the organization and the Ministries of Health and Community and Social Services for the funding to support Morgana.

Linda let them know that it would take some work, but it would be worth it in the long run. She helped Morgana's Mom figure out who to call. She helped them think about what to say. When they needed to write letters, she coached Mom.

Mom says, "Linda would make suggestions about what to talk about, and how to word it. She would help edit and tighten the message we would write. As a parent you just get lost as to what to say. After we sent the letters, she would check in to see if we had heard anything, and suggest that we should call them back. I am one to sit back and wait...especially when I am feeling drained. She was there to just give a nudge. I don't know where we would have been without that".

Facilitators work to make it easier for people and their families to access what they need to create the support that makes their vision possible. And then Facilitators walk with them as they learn how to manage these resources.

planning

John O'Brien, in his article, ***Person-Centered Planning and the Quest for System Change***, speaks about the type of planning that Independent Facilitators do as the following:

"Person and Family Generated Action-Learning...created by people and family members with their allies. It is often supported by skilled facilitators who act independently of any service (Lord, Leavitt & Dingwall, 2012). It can exist at the edge of the system, outside publicly funded disability services, or it can mobilize a partnership with service providers and system managers committed to innovation. Self-directed individual budgets multiply the resources available. Person-centered planning in this context can open new pathways to valued community roles. Skilled facilitation can create a deeper understanding of a person's identity and capacities, extend resourcefulness and initiate the creation of new forms of assistance."

Independent Facilitators support planning with people in two basic ways:

PLANNING PROCESSES THAT GENERATE A PLAN DOCUMENT

For almost 40 years, person centered planning has been developed as methods of gathering knowledge about a person, generating visions, identifying resources, and planning action steps that lead to change.

Many of these methods identify a process for exploring guiding questions that can lead to the creation of a document that serves as a blueprint for collective action to create change. Some of these tested methods include, Personal Futures Planning, MAPS, PATH, Essential Lifestyle Planning, and others.

These documents provide a collective reference that gets all of the players "on the same page", and can serve as a point of reflection and accountability. We can use the document or image created, to check on where we are along the way. We can share what we are trying to do with new people we want to invite to join us.

These methods and processes are particularly helpful when many people, like a support circle, or multiple organizations and funding sources are involved. They are helpful for a big change, like moving out of the family home, or settling into a new community.

Most Independent Facilitators have learned and developed skills through practice with some of these methods. These methods and the documents generated are the most common understanding of what “Person Directed Planning” is.

A PLANNING RELATIONSHIP -- STEP BY STEP “MICRO PLANNING”

Independent Facilitation is an ongoing relationship, a partnership journey that supports people to direct their own lives, and the support they need to live as citizens and community members. It is rooted in listening for what is important to people at any given moment in time, and planning to act in a step by step way.

Many people have not had the opportunity to develop their own vision of the life that they want to live, and the support that they will need. Their relationship with a Facilitator is a place to explore ideas of interest, plan to do something, follow through, and then discover what they can learn from these smaller plans and actions.

Beth wanted to get a job. Judy helped her to identify places where she might work. They found a local restaurant that needed some help in the kitchen. Judy helped Beth think about preparing for the interview. Beth got the job. Since Beth started working, she and Judy talk about the job and how it is going. Beth wants to see if it would be possible to get out of the kitchen and work with customers. Beth decided that she also enjoyed working on the farm, and wants to explore working in a greenhouse.

"Right away we got to work by talking about what I wanted to do and what would be a first things to start with. Within a very short period of time, I was volunteering at the Local Food Co-Op, connected with an employment service, explored the local music scene and I got a part-time job at No Frills. She really listened to me and acted on what she said she would look into. She introduced me to things I didn't think were possible and I trusted her."

Sometimes a crisis hits, and planning is about putting one foot in front of the other to get through it. Shurlan's Facilitator, Joanne explains,

"... really complex situations came up where Shurlan was in jeopardy. It was really difficult to know where to turn. His family didn't know where he was, and I didn't know, and there really wasn't any obvious next steps. It was really a dangerous predicament.

And so it really took a lot to work together to find out what system is he in, through the police system or the hospital system, to figure out how can we support him, and move forward with this, which was a really intense situation.

There wasn't a lot of information. Nobody knew where he was, or what was happening next. So between the two of us (Mom and Joanne), we could figure out, "OK he's here. Here's the next step. Here's the telephone number..." So we were both on the same page. And we also knew what had to happen next, to support him, and to support her, because there really is a role to supporting her to manage through that very stressful situation."

In any given year there will be many of these "micro-plans" that develop in the relationship.

For everything there
is a season, and a time
for every purpose
under heaven

Ecclesiastes 3:1-8

Independent Facilitators need to sense what the best approach would be for the people involved at that particular moment on their journey. The foundation of successful facilitation depends on building trusting relationships with the person and their family. This takes skills and time.

Things Happen and Change

Things do happen. Things change. And sometimes crisis shows up unexpectedly. Facilitators walk with people as they move forward. They stay with them when “life just happens”. When issues of health, death and grieving, emotional upheaval, legal and financial matters... stuff just happens, and Independent Facilitators, plan, act, and learn together with people and their families.

Larry lives in his own place now. He has support that comes to his home. Larry's aunt, visits frequently, and feels Larry, "...looks much happier." Mom shares, "He is getting back what he had before. He is set up with his TV, computer, he has space...he has access to help if he needs it."

Larry adds, "I feel my life is back on track...I feel great, fantastic."

But Larry, his Mom, and support circle know that life happens, and everything can change in a minute, so they enjoy while all is well, and know that they will be able to get through whatever comes their way...together.

John says, "Despite still be on all kinds of waiting lists and waiting for funding, I left my parents' home. It's been 7 months since I moved into my own apartment and Dennis stays with me. It took me a long time to figure out that I can't stay alone. It's been 7 months that I haven't touched drugs. Dennis is my rock and because of my facilitator who

made those connections with me, I have hope. Now I have friends and people beyond my mom and dad who are in my corner. I feel supported and stronger than ever before. Life went from impossible to possible. For the first time in my life, I'm paying my own bills, and I have money leftover. I'm so proud of that.

Housing is very expensive where I live but with the help of a bigger circle that includes people like Dennis, Diane, Ron, mom, dad and as important my facilitator I think someday I will be a home owner. I still have my struggles and right now I just finished a sleep clinic because I have sleep apnea really bad. It's hard to find the energy and strength each day when I'm so tired. But that's ok because I'm riding this train as long as possible, I love my life and the people who have helped me get this far."

Beth has had so much happen. She has a job. She has friends, including a boyfriend. She is involved in her community. She has matured. She is actually happy, and her Mom has watched these changes. Beth wants to move off the farm into her own place in town, but her family still has concerns. Beth says, "I am grown woman and I need to start taking care of my life." She has changed. She manages her money. She sticks to her commitments. There is a second house on the farm, and Beth moved into it about 6 months ago. She saved her money, and bought some furniture to replace the old furniture. She worked on setting up her place with her Mom. Their relationship is changing. They have grown together.

Now Beth is imagining life ahead, another job, moving into town. Lots more to do.

Morgana is moving into her new home this month. She will have her own staff, use her ODSP to pay for costs of living, and continue to be connected to her parents as they will be close by. She is very excited and has been decorating and preparing for the big move. Morgana, and her Mom and Dad know all too well just how fragile life is. Three weeks before Morgana was scheduled to move, the young woman she was going to share her home with, passed away. There is deep sadness for Morgana and her parents as they had been getting to her housemate and her family. Morgana's Facilitator, Linda, is with them as they prepare for the move, grieve the loss of a new friend, and look to the future. Mom says, "Without Linda, we would still be sitting here, stressed, overwhelmed, exhausted, and not knowing what to do."

Lily said, "I just want to be free". As a result her circle supported Lily to change her schedule to go to the day program once a week. Lily will be returning to her job in May. She will also be exploring other things to do to keep busy. Lily has learned to take the bus to get around.

"One thought that comes to mind significant in our family is the support and relief that Lily's mom feels because of the guidance you gave us. Her ability to cope and physical health is much stronger." There is still lots more work to do to find the living arrangement that will work best. Lily has already stated she wants to live with a friend.

Shurlan made it through a scary crisis. He ended up having to move out of his family home, and temporarily lives in a group home where he has individualized support, while his life stabilizes. He's looking forward to the future when he can "meet new people, and try new stuff."

who can benefit from independent facilitation?

Independent Facilitation can benefit anyone who is seeking person directed, individualized, community first support. But there are some people for whom this kind of support relationship may be particularly beneficial.

who can benefit?



- **People who have COMPLEX circumstances**

People who have circumstances that no existing service is setup to deal with. People whose lives and support needs involve more than one government funding source, or multiple service agencies. People who have issues related to health, mental health, addiction, and disability. People who have faced dangerous situations, homelessness, and jail for example.

- **People who have access to LITTLE OR NO FUNDING resources**

There are many people who are on waiting lists for resources, or have only been allocated small amounts of Passport or other individualized funding sources. These situations by necessity require looking to the community for people, places, and resources that can support people.

- **People who have had NEGATIVE OR HARMFUL EXPERIENCES with services**

There are people who have been engaged with existing local service agencies, who have had a negative, harmful or traumatic experience. Trust has been broken with these people and their families and engaging existing service models does not feel like a desirable option for them.

- **People who want to be IN CONTROL and self-managing support**

There are some people, and families, who simply want to be in control of their support system. They are simply not interested in losing authority by handing off responsibility to the management and leadership structure of a service agency. Self-managing support services requires intensive skilled and relentless work. The advantage is that by ‘personalization’ some unique and remarkable outcomes are possible. It is a big undertaking and not for the faint of heart.

- **People who are NOT INTERESTED IN A SERVICE AGENCY**

There are people and families who are quite aware of the kinds of programs and services offered by local agencies. They have not seen anything that fits their vision, or their understanding of what kind of support they really need. This is particularly true in smaller, or rural communities, where there are extremely limited options. In some rural communities, receiving support from a service agency often means leaving the community where they, their family and allies live.

- **People who are in TRANSITION FROM SCHOOL**

There are people who are leaving school to establish life as an adult. Their focus is on participating in the community, and becoming a citizen. They have not yet entered into the service system and “programs”. Their family may have used SSAH funding to hire support workers who accompany them as they participate in community places, associations, and activity. They want to build a “community life”.

- **People who HAVE NO FAMILY CONNECTIONS**

People who have no family connection are at very high risk of living their whole lives in “service land”. If their advocacy for a different/better life gets labelled as “behavioural”, they are further at risk of being given psychotropic drugs, use of restraints, isolation, incarceration, etc. These are people for whom Independent Facilitation is especially important.

- **People and families who are AGING and need LEGACY PLANNING**

People and families are aging. Parents who provide a substantial share of personal supports reach their own limits of health and aging. People with disabilities now live much longer, so are a new challenge for support and health care.

- Anyone who is interested in becoming or is already an **INDEPENDENT FACILITATOR...**

Part C: references

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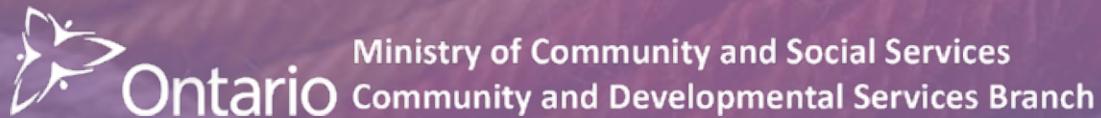
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learning so far...

weaving a story of change

The Independent Facilitation Demonstration Project



Part D:
the challenge of getting started

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facilitation
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emerging communities working to make independent facilitation possible

The first challenge for the IFDP project was to establish or renew the seven initial Independent Facilitation Organizations (IFOs). Funding instability dictated that several needed to renew and rebuild before they could grow.

Of the communities that the IFDP reached out to engage, four communities were supported to explore the possibility of Independent Facilitation as a viable offering to people and their families in their community.

- Thunder Bay,
- London,
- York Region,
- and the Near North (including Parry Sound, Huntsville, Timmins etc).

Each of the communities used IFDP resources to educate people and families about the potential of Independent Facilitation as a support for their lives and visions.

Each community offered learning opportunities for people interested in developing knowledge and skills that they could use to offer Independent Facilitation as a practice that could serve local interested people and families.

IFDP made it possible for local people to participate in provincial events offered through the OIFN: Community of Practice Forums, and the Common Threads: Changing Stories...Stories of Change conference.

The experiences of these communities over the last year have generated enthusiasm, knowledge, and connection. Local Steering/Planning Groups have formed to organize, bond, and clarify visions for action.

This has been fueled by volunteer effort, which means that progress is slower than people would hope, but continues anyway.

This section addresses some of the challenges that were discovered as people ventured to innovate locally. The community development and community building work is the right investment to bring this offering forward in these 4 communities. The OIFN submitted a proposal (Schedule D Reinvestment Fund) to support and continue this work.

HOW DO YOU START AN IDEA THAT HAS NEVER BEEN SEEN?

Independent Facilitation is not a new idea. It exists in pockets around the world, where some version of “Independent Facilitation” as —a supportive relationship, not tied to direct services, that assists people and their allies in planning and acting to create change —whether it is called a Community Facilitator, an Advisor, or a Broker, etc.. However it is not widely known that it exists as a means of support for people and their families. Most people in communities across the province have never heard about it, or have never seen it in operation before.

How do you describe something that people cannot or have not seen? It is like trying to describe an orange fruit to people who have never seen the colour orange, or tasted the fruit.

There are some particular challenges:

- People and families do not know that there actually has been a history of this development that has been in line with the advocacy efforts associated with individualized funding, and a movement to individualize and customize support that is defined and controlled by people and their families.
- People and families do not know what they do not know. Many people and families are isolated and disconnected from other self advocates, or family groups and networks. They are not connected. In fact the development of the DSO system has actually exacerbated this because now people and families cannot directly connect with service agencies, where they might find

connection with other families etc.. In most places the DSO is making people aware of services that are available or not available. They are not connecting families to other families, individuals to other self advocates. So people are left in the dark.

- There is confusion that comes from the unclear use of language, and language that makes things sound the same as something else that is very different. The Ministry's Person Directed Planning and Facilitation Guide says,

"The three terms used in the guide: person centered planning; independent facilitation and planning; and person directed planning have evolved in a unique manner in Ontario, somewhat distinctly as compared to the experience of other jurisdictions."

It is no wonder that people might be a little confused about what we are talking about.

John O'Brien is an internationally respected leader in the field of human services and developmental disability. He has rich perspectives on the evolution of services over the last 40 years in Canada, the US, and around the world.

The table below is adapted from O'Brien's article, ***Person-Centered Planning and the Quest for System Change*** and captures observations of different ways that Person Centered Planning has been used:

Function	Actors	Initiator	Intended Benefit
Service Planning	System management engages person	System Service Coordinator/Case Manager	best fit for person in available services
Support Planning	System management, and person, engage service provider	System Service Coordinator/Case Manager (ISP)	identify goals and outcomes for service delivery
Service Improvement	Service provider engages person	Service provider	make existing services work better
Customized Employment	Employment Facilitator with person and network	Employment Facilitator	identify gifts and capacities that have economic value for employers
Innovation Through Partnerships	Service Innovator engages person	Service innovator	identify new service offerings that could be more person directed
Person and Family Generated Action Learning	Person + allies engage community settings and, when necessary, support providers with assistance of independent facilitation	Person and allies	Pathway to valued community role and establishing desired partnership with service support, individual workers and providers

While all of these use the language of “person centered planning”, the purpose, process, and outcomes are very different.

People and their families may be familiar with one of these functions, and decide that they do not see the value of that investment for their purpose, especially if they think they have to spend their precious Passport dollars at the expense of the direct support that they require to survive.

In Part C: What Is Independent Facilitation and Who Can Benefit?, we highlighted that Independent Facilitation is aligned with Person and Family Generated Action Learning. This is among the least available or funded modes of Person Centered Planning, and as a result few people have ever seen it in their community.

In addition, in Part C, we also identified that Independent Facilitation most often takes the form of A Planning Relationship—Step By Step “Micro-planning”. (see Part C). This is significantly different from the other modes of developing “a plan” that are listed in the table above.

historical context challenges

Independent Facilitation grew out of the movement of self advocates, families, and service allies advocating for individualized funding that could enable people to have control over their lives and the ways they are supported.

Historically, funding has been provided to service providers to offer “programs” that have a limited number of “spaces”. Many people and their families have sought support from service agencies, and gained “a space” in a program that has “vacancies”. This means handing over authority to the agency for how resources will be used and managed. These services are “program directed” not people focused. People either fit into how these programs are managed, or not.

People and families experience of existing “program” models of supporting people limit their ability to direct their own lives. They have felt that there was a need to create something new that would change the outcomes in people’s lives.

Receiving direct funding would mean that they would have to create the “individualized” model of support, and how it would be managed. Independent Facilitation is, and was, one part of innovating new models that could replace the old “agency directed group models”.

“There is an identified need for cultural change related to "new ways of doing business", including training for families and staff, and transition strategies to support organizations... centering on the person requires a change in the values, knowledge, and skills throughout the system a single focus on staff training will not be sufficient to create the changes in values and knowledge Many agree that this process of change would be much easier if everyone could "start from scratch".

(Ontario Ministry of Community and Social Services (1994)

Independent Facilitation is a “start from scratch” effort to enable the possibility for each person to innovate and create something new that is customized to work for them over time, and as their life changes.

start/stop “project” challenges

This effort to innovate and develop new models of support has been driven by families and self advocates.

The Ministry has recognized the limits of old models, and has periodically invested in “projects” in various communities to explore new possibilities. The difficulty is that “projects” end. To date the only “infrastructure” that has remained is the availability of direct individualized funding (Passport), that allows people to choose to spend up to \$2500 of these extremely limited resources on “person directed planning”.

The Independent Facilitation Demonstration Project, is another Ministry project investment designed to explore what it would mean to expand the number of people and communities that could provide Independent Facilitation as a service offering that is not paid for by the limited Passport dollars available to people.

Such projects by their nature have a limited life. They will end. Up until this point local communities and groups that have undertaken “projects” have been left having to figure out how they can continue after the project ends. To date the Ministry has not established ongoing infrastructure resources, in particular sustainable funding, for an Independent Facilitation service offering that people support without using limited Passport dollars.

The result has been that some communities that have engaged in these projects have been unable to continue what they began. The result has been that hopes and excitement grew throughout the project, and then were dashed by ending the project.

This let down has been expressed by people in Thunder Bay, London, Hamilton, Huntsville, and York Region.

For many people and their families, this experience is more than a let down, it is traumatic. One mother expressed how the project that she and her son were involved in had made it possible for her son to live in his own home, hire his own staff, choose the what,

where, and when of how he spent his time. He was quite happy about it all, and his Mom felt that stable the life she was hoping to see established before she died was well on its way. When the project ended, life continued as it had been developed in the project for a while. Eventually the infrastructure to support her son's life dissolved. Eventually he had to move into a home managed by an agency with two other men who required support. In many ways he lost the power to direct his life. Now, his mother is much older. She does not have the same energy she had 20 years ago to start over. Even more relevant, she has lost hope that things will change. Hope for change is a key source of energy to do the all consuming work of creating something new.

“who cares?”

an eco-system of relationships for successful innovation

Windsor-Essex Brokerage for Personal Supports emerged through a network of collaborative relationships that developed a “pilot project” in the late 1990s. It rallied “people who care” about something that was bigger than their small part:

“A broad understanding of how people have been excluded in their community has shaped the thinking and the work of the community partners —People First, service providers, family groups, government, and community organizations. As a result, they have looked at every aspect of the service system. They sought to redesign the planning system, the funding system, the process for community development, appeals processes, links between agencies, community supports that would be available, etc.. A community services system that had evolved over decades was being examined by the very community who had developed it. But it made sense to the partners to do so. They are committed to making it more responsive to the aims of individuals and families in their midst.

...the vision was to create an independent planning support capacity; “unencumbered” assistance to individuals and families to plan for the future, and to arrange needed services and supports. It was to provide direct accountability to individuals and families in planning supports, and help open doors to options in the community that had remained closed for too long.”

*Windsor-Essex Brokerage
Pilot Project Evaluation Report
The Roeher Institute 1998*

When the “pilot project” ended in Windsor-Essex, this interconnected network of “people who cared” about a vision that was bigger than any one of the parts, continued to work together to find ways that the “unencumbered” support offered by Windsor-Essex Brokerage for Personal Supports would continue.

In so many ways, Windsor-Essex has continued its success because of the strength of the ongoing shared commitment of this collaborative network “to provide direct accountability to individuals and families in planning supports, and help open doors to options in the community that had remained closed for too long.”

However, in the time since the Windsor-Essex pilot project, the Ministry has implemented a “Transformation” policy which means it a priority to create a fairer access to supports and services across the province. It is not enough that a key service offering is available in one, or even a few communities.

There now must be a way for such a valuable resource to be more widely available. This was a primary task of the Independent Facilitation Demonstration Project—to learn about what it will take to expand Independent Facilitation service offering to more people in more communities.



In March of 2016, the Stewards of OIFN envisioned what would be necessary for Independent Facilitation to last beyond the “project” phase in the communities. The Steward vision mirrors the learning of the Windsor-Essex pilot project:

To offer “unencumbered” planning and customizing support through an ongoing relationship with an Independent Facilitator who is accountable to the person, and their family, to be able to thrive in communities across the province, the following

components of “an eco-system” of relationships that need to be strengthened:

SELF ADVOCACY GROUPS AND NETWORKS

The heart of this work is the accountability to people directing their lives and the support they need to live as adult citizens. The only people who truly know and understand the experience of living as a person identified as “disabled”, are people who have this experience. The presence and involvement of self advocates is essential to developing a system of services and supports that are “person directed”.

FAMILY GROUPS AND NETWORKS

Families have been the key leaders of change that focuses on person directed, individualized, community first, support. Family groups and networks play a critical role in strengthening and energizing families. Families are empowered through the information, knowledge, and experiences that they share with one another. For most people, families are the people who will be there for support, long after any policy changes, agency leadership retires or moves on, or support staff leave.

INDEPENDENT FACILITATION NETWORKS AND COMMUNITY OF PRACTICE

Independent Facilitation is an ever evolving practice of supporting innovation in an individual person’s life as people grow and change. No two people are alike. No two individualized support models will be the same. Facilitators need a network to turn to for continuous learning exchange that expands the practice, and skills of Facilitators.

MINISTRY ALLIES AND RESOURCES

The Ministry plays an incredibly important role as the source of resources that shape the nature of services, and ultimately the outcome of services and their affects on the lives of people and families. The Ministry faces huge challenges as existing models of service developed in an earlier time for different purposes continue to be funded, while new models need to be developed to address current and future realities. Access to individualized funding is critical to the development of person directed

support that leads to citizenship and community membership. Funding needs to be available to develop new infrastructure and service models that shifts focus from “agency directed program” spaces, to person directed individualized support.

SERVICE AGENCY ALLIES

Service agency allies also play a critical role. Many people require direct support in their lives. They need people who can:

- support them to take care of daily life needs;
- assist them in developing skills to do more on their own;
- accompany people into community places as they become known.

Currently the bulk of direct support resources are organized through programs delivered by existing service agencies. These programs and the infrastructure to support them were not developed for person directed individualized support. Forward thinking service agency allies are needed to re-imagine new forms of support and infrastructure that can align with person directed individualized support.

WE ARE EITHER WORKING TOGETHER OR WE ARE WORKING AGAINST EACH OTHER

Independent Facilitation is not the vision or goal. The vision is people directing their own lives, receiving support that makes it possible to find their rightful place in community as a contributing community members and citizens who belong. Independent Facilitation is one innovative model that holds this vision as its only reason for existing. There is plenty of room, and a vital need for other innovative models and infrastructure to be developed.

If stakeholders in community do not hold this vision as their sole reason for being, they will be actively or passively working for another vision. In the process they will be holding on to resources of people, money, assets, and places for other purposes. This will restrict what is available to create something new, and divide the community. It may not be the conscious intention, but it will be the outcome...a community weakened by divisions, and severely limited resources for inventing the future.

thunder bay insights and analysis

The Thunder Bay Independent Facilitation Steering has a mix of members: parents, Family Network representatives, Service Agency leaders and staff, and College Developmental Service Worker program faculty. Currently, there is no involvement of Ministry staff or from self advocacy groups. At a recent reflection meeting in Thunder Bay (supported by the IFDP), the group provided insight into the challenges, barriers, or obstacles to getting started with Independent Facilitation.



ATTITUDES-- HEARTS AND MINDS CHALLENGES

Our attitudes are shaped by what we see and experience.

Many people and families have only seen services as they exist today — programs directed and managed by service agencies, mostly group programs. Agencies design programs that have room for limited numbers of people. People wait on lists until a “vacancy” opens up in the program.

Developmental Service Workers are hired for the programs to work with whoever is in the program.

One of the members of the Thunder Bay Steering Committee teaches students in the Developmental Service Worker Program at the local college. The curriculum in the college's program is heavily weighted to “person centered practices”, community, and citizenship. She observes the enthusiasm in the students and the clarity of their ideas while they are studying. She often gets the opportunity to visit agencies where students are employed after they graduate. She notices the students' ideas, language, and practice has changed. The reason is that as much as people value person centered values, programs are designed for different purposes —to support and manage the program—and new staff learn how to fall into line with the 'mainstream culture'.

Neighbours and community members only know what they know. If they do not know someone with a developmental disability, they most often inherit the social prejudice that exists regarding people with developmental disabilities, and are confirmed by the placement of people in “special programs”, or the way support workers relate to people they support in public places.



People's thinking is also shaped by emotions generated by experience.

Financial realities have generated a scarcity mindset that fosters fear, distrust, and protection.

People with developmental disabilities are by design, poor. They are most likely to be unemployed, or underemployed. Even if they have work, they have to balance their desire to earn money, with the negative impact their earnings have on the ODSP benefits.

Families are often impacted financially by their loved one's support needs. It is not uncommon for parents to have to leave a job to stay home with their son or daughter when they become adults and no longer go to school.

Direct funding Passport resources are most often seriously limited given that there are 168 hours in each week, and available funding only covers a small portion of that time. Families are often desperate to stretch these resources to get the maximum number of hours that their son or daughter have in a supervised place. This scarcity experience is seeing the development of privately run small group programs that people are paying for with their limited Passport dollars. The individualized direct funding is now being used to recreate group programs.

Agency programs feel forced to use the financial resources that they have in ways that limit choice, even though they may want to support people individually.

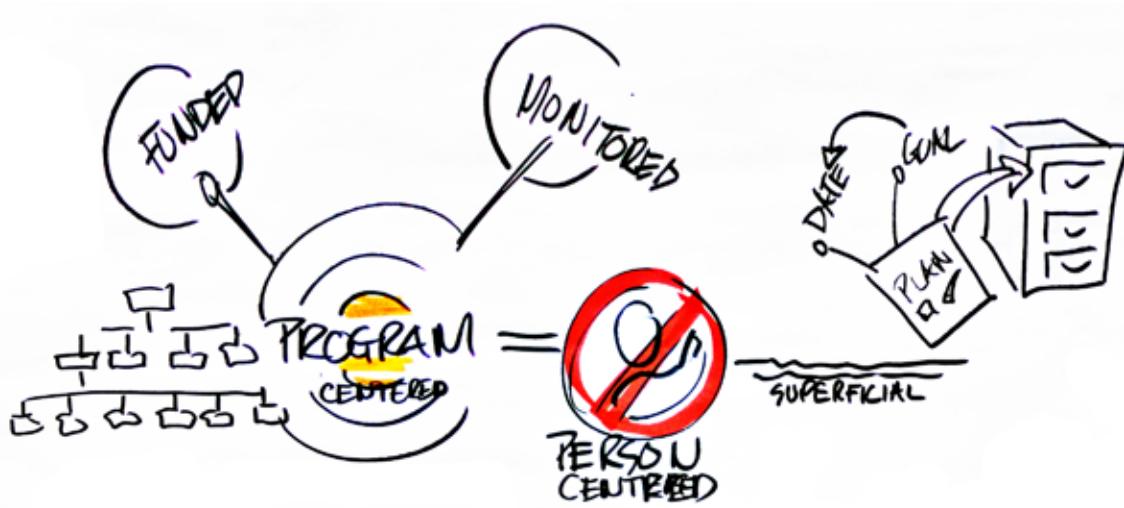
Scarcity breeds protectionism. People and organizations hold on to what they have, and distrust others for fear that they may lose what little they have.

STRUCTURAL CHALLENGES

Local agency staff and leadership identified that the services they provide are “program centered” and agency directed. Their organizations are contracted and funded to deliver programs. There are so many “spaces”, “beds” that they are contracted to offer.

Their human resources departments policies and practices are designed to staff programs, regardless of who is attending the program.

They have acquired buildings, offices, housing to accommodate the staffing, and people who occupy the “beds” and “spaces”.



They are “monitored” by the Ministry to ensure “quality” and “safety” according to policies, rules and regulations that have nothing to do with an individual person.

They have established “person centered plans” as a means of keeping track of this monitoring. The plans are annualized, and are tracked for when they happened, who attended, what goals were identified. They are then put into a filing cabinet, in case somebody needs to follow up later, usually because of a problem that arises and

could cause trouble for the agency or the Ministry. At best these plans are superficial.

These agency leaders and staff are members of the Steering Group because they know that something else is needed to change the structures that are so rooted and actually toxic. Independent Facilitation can help people identify what they really need from the service system and what infrastructure alternative options could emerge. In an effort to prioritize the need for the use of limited base of taxpayer dollars to serve people who are most vulnerable, the Ministry has inherited a model of “problem focused funding”.

The professional sector of medical doctors, psychiatrists, and educators, use various methods and diagnostic tools to identify “how bad is your problem?”

To approach the DSO for support, parents have learned that they need to speak and think about the person they love in the most problem focused way, because they have learned that if they are not in crisis, they will not rise high enough to access the resources they need.

This experience of having to paint such an awful picture of the person they love, is traumatic.

It is not uncommon for families to own the view they have been sold by professionals and a system that needs them to be extremely needy. When this happens, the energy needed to be innovative, and mobilize to generate new ways of support is completely depleted.

The families and allies who need to mobilize people around a new idea find that they cannot convince families to see any other possible options.



PRACTICAL CHALLENGES

There are practical challenges that the people in Thunder Bay have discovered.

Potential leaders among families are simply exhausted by the ongoing effort to stay afloat. In Thunder Bay, there is also the post traumatic experience of the CHOICES Project that began with such promise, and disappeared. The memory of this lives in the lives of those families who participated and had been passed on to later generations as a painful experience of loss.

The biggest issue is, if we actually develop the capacity to offer Independent Facilitation, where will the money come from? To date there has been no indication that the Ministry will provide funding for a service offering called “Independent Facilitation” expansion into new communities.

The only possibility is for families to pay out of pocket for the services of a Facilitator, or by using 10% or up to \$2500 of their Passport funding allocation. This is just not possible given the amounts that people are receiving, if they receive anything at all.

Finally, in the support eco-system of Thunder Bay, and other communities, the regional and provincial Ministry staff are distinctively absent in joining in on the bigger vision of “redesigning the planning system, the funding system, the process for community development, appeals processes, links between agencies, community supports that would be available, etc.”

So the necessary alliances are only beginning to grow, and there is so much more to be done.

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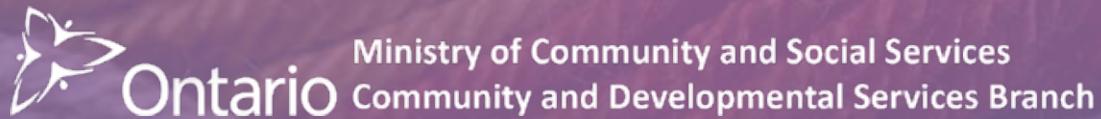
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The Independent Facilitation Demonstration Project



Part E:
looking forward

learning so far...

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investments in independent facilitation in the context of system change

It is essential to consider the investment in the expansion of a new service offering—Independent Facilitation—in the context of the broader system change.

Since the early 1980s the Ministry has recognized the value of supporting children to live in their home community, surrounded by the people who love them who can offer more support than any service program could ever offer. The SSAH was initiated to make it possible for families to get support to remain strong, and their loved one to be supported to live and participate in their home community.

Recognizing the value of this kind of assistance the Ministry developed the individualized direct funding resource provided through Passport for adults in 2008.

The Developmental Services Transformation (2006) and the Social Inclusion Act (Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008) recognized some significant problems faced by the Ministry, and people and their families throughout the province:

- there are more adults with developmental disabilities in the province who are not served by traditional services (residential, day, employment) than are being served
- it is not financially feasible to expand the existing service program models to serve all people with developmental disabilities in the province
- a significant portion of the population of people with developmental disabilities do not believe that existing developmental services programs meet their individual needs, nor support their vision of life as citizen and community member
- current funding models and contracts with community based developmental services agencies are not designed to enable or promote person directed

individualized service models that are flexible and responsive to individual needs and visions. An Executive Director of a service agency put it this way:

"The real struggle is that we're operating within a system that still relies on block funding. It's nice to say we should plan individual by individual, but as an individual moves with his or her money, it leaves a gap with no way to fill it. The money exists within our system, but it's tied up in so many ways that we have to evolve the system in order to respond to individuals."

Malcolm Jeffreys

ministry commitments and challenges

The Ministry committed to eliminating some waiting lists for services in the province in 2014. Waiting lists for SSAH have already been eliminated ahead of schedule. Waiting lists for Passport funding will be eliminated in 2017-18.

Direct individualized funding through the Passport funding option is the primary means of addressing this inequity for adults. People may receive up to \$35,000 to access or develop support that can work for them. The resource is incredibly helpful, and is a huge improvement over having nothing.

However, there are several unresolved issues:

- While people may receive “up to \$35,000”, most people do not receive this maximum, and many receive far less than the maximum.
- For people receiving support through traditional service programs such as a group homes, the median cost of a “bed” in a group home is \$93,000 (Ontario Auditor General 2014) —people who live in group residential programs most often require other programs that support them on weekdays. The costs associated with overall support is well over \$100,000. The Passport maximum allocation is less than 1/3 of the support offered through residential/day/employment programs. But many still face whole life challenges.
- When people and families receive Passport funding they face the challenge of managing these limited resources efficiently and effectively to serve their vision and needs. They face this challenge alone. There is no system wide resource to support people to manage the direct funds available to them. Some local service agencies offer support for delivering direct support workers. However, one mother shared the challenge of this offering:

"My daughter Morgana, is 31 years old and lives at home with me and my husband. She has Spina Bifida and uses a wheel chair. She requires attendant care support to meet her daily physical needs. She also has significant medical issues that require ongoing attention and care. My husband and I both have to work.

The CCAC provided us with some in-home support offered through a local agency on weekdays in the afternoon/early evening. This support can only be provided in our home.

We received \$20,000 in Passport funding. We approached the local service agency in our community about assistance with hiring direct support workers who could support Morgana in getting out in the community each weekday, where she has been a volunteer for more than 10 years.

We needed someone who could come to our home in the morning, get her ready —cleaned, dressed, and taking care of her catheterization, before using our accessible van to take her to the places she needs and wants to go each day.

The local service agency was wonderfully open to assisting with this. We were grateful and hopeful. As time went on we discovered some significant challenges. The agency could not provide workers at the time in the morning we needed them (while I was getting ready to go to work).

They could also not guarantee that the same person would come each day. There was no "regular" staff person each day. We were unaware who would be coming on any given day or week.

Finally, the administrative fee for this service made the cost almost twice as much than if we hired on our own. We could not afford to lose the direct support time. We also needed to have consistency, so that Morgana knew who would be supporting her each day. So we ended up doing the hiring ourselves.

This works much better for Morgana. But I am exhausted from all that it takes to manage the people, the money, and all of the paperwork that is required.”

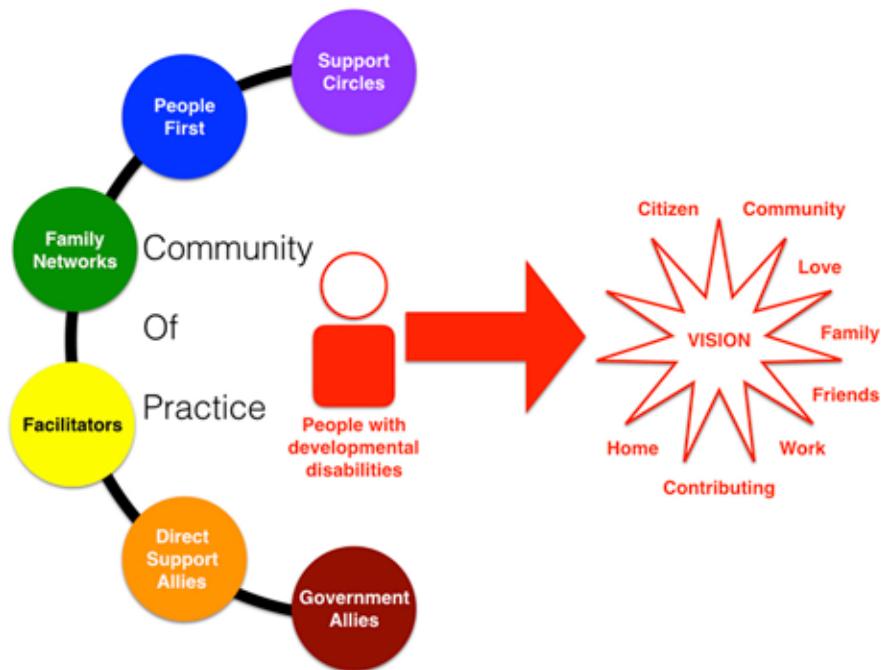
- There are no clear solutions to issues related to affordable, accessible housing in Ontario. People and families are left to sort out where they can live on their own.

“two loops” in the emergence of social innovation

Margaret Wheatley and Deborah Frieze in their article Using Emergence to Take Social Innovation to Scale ©2006, say the following:

Despite current ads and slogans, the world doesn't change one person at a time. It changes when networks of relationships form among people who share a common cause and vision of what's possible. This is good news for those of us intent on creating a positive future.

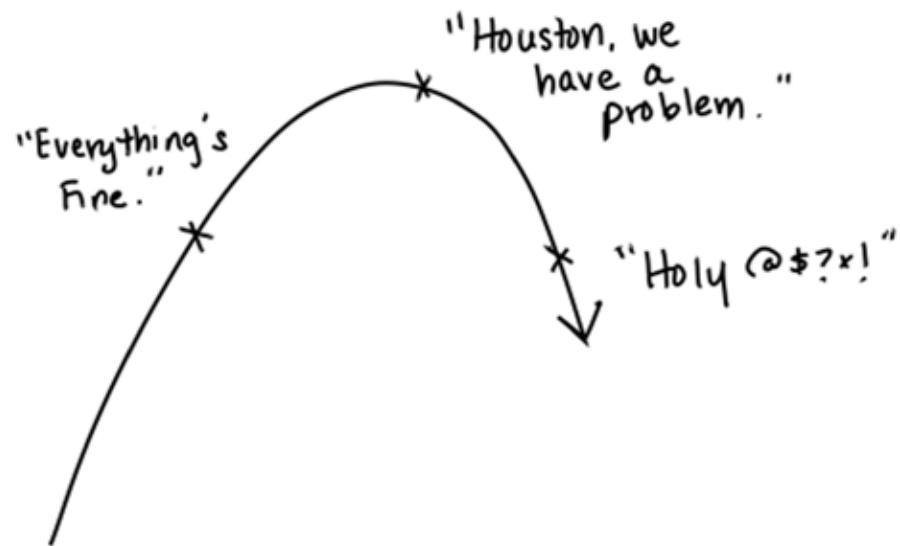
The early experiences, and ongoing resilience of Windsor-Essex developing “Independent Brokerage Facilitation” is a testament to this. The image below captures the collective focus.



Since that time other communities have, to greater or lesser degrees, developed some version of these collaborative relationships. But it is not widespread. For this kind of change to happen, some version of this “common cause” vision is necessary.

Wheatley and Frieze, through their work at the Berkana Institute capture the evolution of innovation as 2 loops. The first of these loops surfaces the “problem” that requires innovative solutions.

What Time Is It?



What Time Is It? The 2 Loops
Wheatley and Frieze (Berkana Institute)

It would appear that the Ministry reached a deep understanding of “Houston we have a problem.” in the mid 2000s with the emergence of “System Transformation” (2006) and the Social Inclusion Act (2008). This arc of the old ways can be represented as the image above.

Throughout the province there are people who have recognized this reality for more than 30 years: self advocates; parents and families; forward thinking service agency leaders; individual regional and provincial Ministry staff.

In pockets around the province, people have attempted innovations that could address this. Independent Facilitation is one of these innovations; service agencies have explored service transformations within agencies, such as:

- Brockville and District Association for Community Involvement
- Community Living St. Mary's
- Durham Association for Family Respite Services

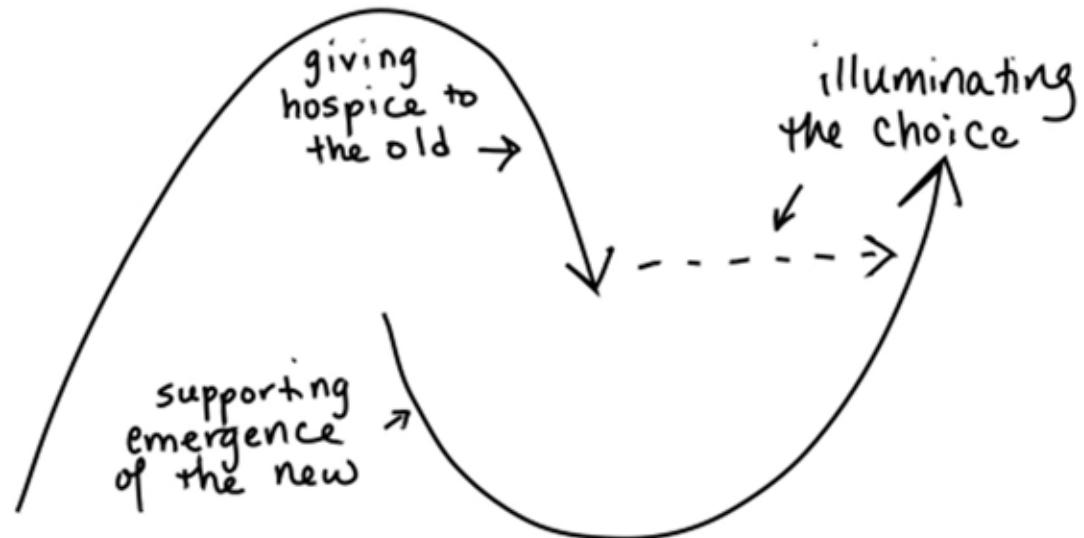
...fostering the development of personal support networks such as:

- Planned Lifetime Advocacy Networks and affiliates...
- Planned Lifetime Networks (Waterloo Region)
- Partners for Planning (Toronto)
- Lifetime Networks (Ottawa)

...decades of work connecting citizens

- Citizen Advocacy Ottawa
- and many more.

Each has been learning different things about the same common cause. The pattern for these innovations are represented in the image below:



Where Are You Choosing To Participate? The 2 Loops
Wheatley and Frieze (Berkana Institute)

moving past a culture of scarcity, and protectionism to networks of collaborative innovation

The Ministry, people with developmental disabilities, families, and service agencies have been plagued by the “culture of scarcity” that just feels like there is not enough to do what needs to be done, so all protect what they have, or what exists now, out of fear of losing it all. The biggest losers in a scarcity culture are people, and those who love and support them.

The IFDP has taught us that there are limits to the idea of simply adding Independent Facilitation as one more service offering, separate from a broader effort to address the change that is needed across the system.

The IFDP has taught us that solutions are not “either or” —either person directed individualized support offered through Independent Facilitation or through agencies. There is room for multiple tracks for solutions, and multiple offerings, that lead to the desired outcome.

The Ministry’s own recognition of the limits of the current system and its inequities is a testament to the fact that there are more than enough people who deserve a range of diverse support options that can support their efforts.

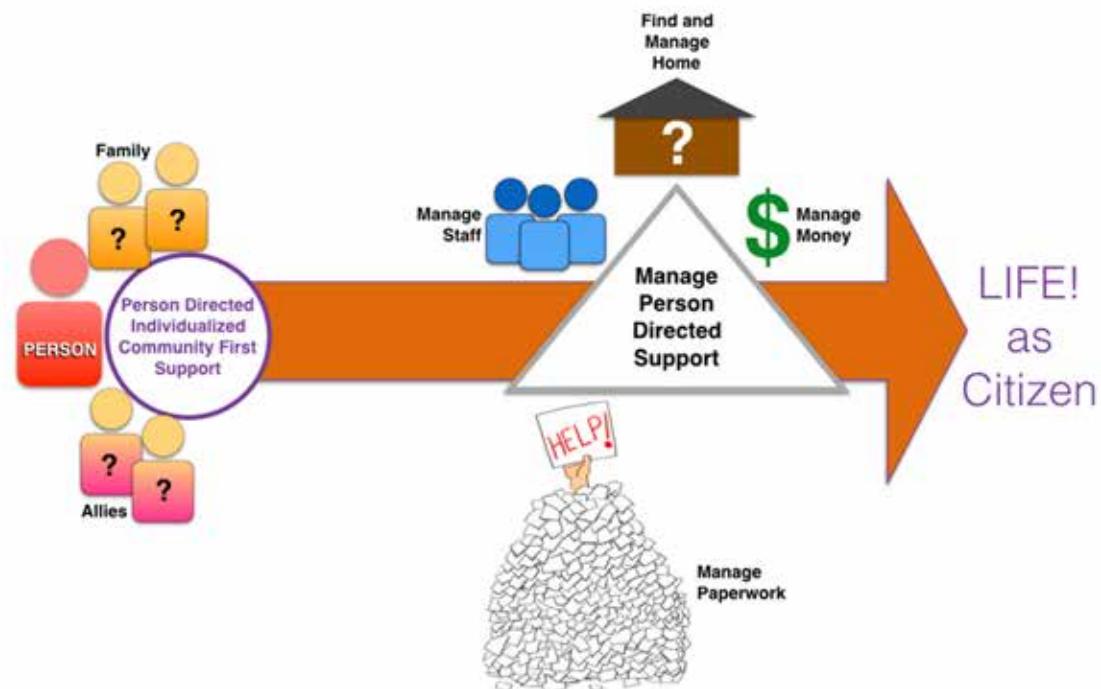
Moving forward there is a need to move past time limited “project” thinking and funding, to collective collaboration toward a desired future. Too many people’s lives are at stake!

Our learning with emerging communities seeking to develop Independent Facilitation offerings has demonstrated that going forward, a wider collaboration will be necessary that includes: self advocacy groups; family groups and networks; Facilitator networks; service agencies; AND the Ministry regional and provincial leaders.

challenges evaluating, learning, and measuring change in innovation initiatives

Independent Facilitation is intended to provide assistance to people and families as they face the challenge of developing “person directed, individualized, community first, support” that makes it possible for them to live as valued citizens and contributing community members.

By definition this is complex work. There is no prescription to any one person’s life, and the support they need. There are no experts who can design complicated solutions. There are far too many variables that are in a state of constant change.



The Ministry has made a significant investment in the IFDP, and wants to understand the impact of their investment. Throughout the Project we have worked with the Ministry to track what was happening in the Independent Facilitation service offering provided, as the work was developing (formative), and measuring the outcomes at the end of the project (summative).

There were a number of challenges that were discovered by this effort:

- The Ministry independent evaluation consultant worked to equate and compare two modes of developing a Person Directed Plan: one mode facilitated by someone outside a service agency, i.e. Independent Facilitation; and the other facilitated by staff within a service agency. But as we identified in Part C: What Is Independent Facilitation and Who Can Benefit there is no uniform definition of Person Directed (Centered) Planning. The context, circumstance, intent, and desired outcome make each offering different. Also it is important to acknowledge that Independent Facilitation needed to created, grow and develop in the compressed time lines of the Independent Facilitation Demonstration Project (IFDP), while traditional service offerings have been well established and fully funded for years. These are not equivalent or comparable.
- The work of Independent Facilitation is about the person (i.e. it is person-directed), so by its nature, cannot follow a linear simple input/output path. Each person's circumstance is different. Do they have supportive family? Are they in conflict with their family? Do they have family at all? Do they have friends and allies? Are they dealing with more than one significant condition—medical, mental health, addiction, homelessness, jail? Do they have any resources to work with —funding, housing, support staff? Do they know how, or do they have people who can help them be accountable for the resources they have access to? And each community faces different realities and relationships with the DSO as the referring body. Does the DSO understand what Independent Facilitation is who would be most likely to benefit? Who is being referred by the DSO? and Why? And the list could go on...

- Traditional accountability measures, such as formative and summative evaluations, are suitable to tweak a program that is already established (formative) or to test if something succeeded or failed. Summative evaluations seek to validate, prove or disprove something. The IFDP was intended to explore the expansion of the availability of Independent Facilitation to more people in more communities. This involved starting from scratch in a number of communities — recruiting, educating, mentoring, community outreach. These traditional accountability measures are less useful in such startup situations.

The Ministry now offers direct individualized funding to adult citizens with developmental disabilities so they may have more flexibility and choice in developing support that works for them. This decision has been influenced by the understanding that people have had limited choices for support offerings in the past, and this has limited their pursuit of life as individual citizens.

It is our belief that comparing two offerings as equals (when they were not) in order to decide which was better, was based on a flawed design. Rather, we could explore what is different, and thus discover which mode would work better for different people in different circumstances.

An important question remains about what we measure and what we learn? And how?

impact learning may offer more insight to system change focus

Developing infrastructures and funding mechanisms for a person directed individualized support system is a radical change within Developmental Services. Governments around the world - Canada, US, the UK, Europe, Australia and New Zealand, have been seeking innovative solutions that make it possible for people with developmental disabilities to live as citizens.

If it is the intent of the Ministry to seed innovations that can address this radical change, then Impact Learning, might be a better vehicle for “evaluation” and learning that can inform policy decision-making and allocation of resources.

Impact learning evaluation processes, such as developmental evaluation, seek to track learning, provide evidence and justification for course changes. Impact learning models are more suitable to complex initiatives, innovations, initiatives with changing contexts and goals that include prototyping, trying things out and refining.

The type of measurement needed depends on what the trajectory of learning is at the time, and mechanisms to capture those measures can change and evolve over the course of the initiative.

Because the intent is learning, rapid feedback, collective sense making and real time adjustments, this type of accountability measure is more suited to independent facilitation. Considering the complexity of the disability system within Ontario, Independent Facilitation impact can't really be measured outside the context of the person and the system within which it is delivered.

An Impact Learning approach would include looking to capture shifts, changes, causality in activities, and actions that lead to change at three levels: organizations, communities, individuals:

- within organizations: (Independent Facilitation Organizations (IFOs), OIFN,

allies, MCSS, DSOs) - agencies connected to or related to independent facilitation work - influences, relationship dynamics, challenges

- communities: (outside of agencies), the actual community that a person and family live in, connect to, and are challenged by
- the individual: the person receiving independent facilitation, and their family members

Potential impact on the field:

- creates a solid knowledge base to build on what has been generated during the first 2-years of the IFDP
- captures what is working and how independent facilitation potentially looks different depending on the delivery agents (community groups in emergent communities; how is it emerging in different communities; small IFOs, more established IFOs such as Citizen Advocacy Ottawa (CAO) or Windsor-Essex Brokerage)
- clear understanding of what people want and why independent facilitation is useful or helpful for their lives
- organizationally - learn and share what it takes to build a strong collaborative structure (with the IFOs), and collaborative intent (as a network linking many actors or stakeholders across the province)

IFOs and the IFDP collaborative learning

The IFDP was designed to explore the organizational model of IFOs (Independent Facilitation Organizations) as a vehicle for delivering Independent Facilitation. Seven IFOs were identified and participated as members of the IFDP Collaborative, organized to learn from each other through the process that emerged through the project.

The expected outcome of the Project was that approximately 1100 new people would be engaged in Independent Facilitation services across the seven communities.

Each IFO was established as:

- an existing organization that had to rebuild or
- a host organization that offers other non-service system based offerings

The funding established for each of the IFOs in the Project was intended to cover three functions:

- Independent Facilitator payment
- development startup costs: initial equipment, Facilitator development and education (capacity building)
- infrastructure, administration and overheads to work with 1097 people

funds available for independent facilitation

At the end of the 2 year Project, the Ministry indicated that the transitional 3rd year (2017-18) would not include the development startup funding or capacity building. The initial startup phase was assumed to be done. For the 2017-18 budget year, the funding available is approximately \$2750/person served. Coincidentally a similar amount (\$2500) is allowed for people to purchase Person Directed Planning services using their Passport dollars.

It is seems clear that the Ministry for either Person Directed Planning or Independent Facilitation. However it does seem that the Ministry has equated Independent Facilitation with a common understanding of Person Directed Planning as a process that results in a PLAN document.

Through the Project it is has become clear to the IFOs that the time involved with people, and the scope of the work that Independent Facilitators commit to, is different than the expected time allotment and scope of work for developing a Person Directed Planning process and Plan document that can serve as a guide for people.

THE DISTINCTION BETWEEN PERSON DIRECTED PLANNING AND INDEPENDENT FACILITATION

The historical roots of Independent Facilitation have been shaped by what people and families say that they need and want to be able to direct their own lives and customize their support using individualized funds.

The Independent Funding Coalition for Ontario's paper, Direct Funding and Accountability: What is of Prime Importance? (2010), identifies what people are to an Independent Facilitator for:

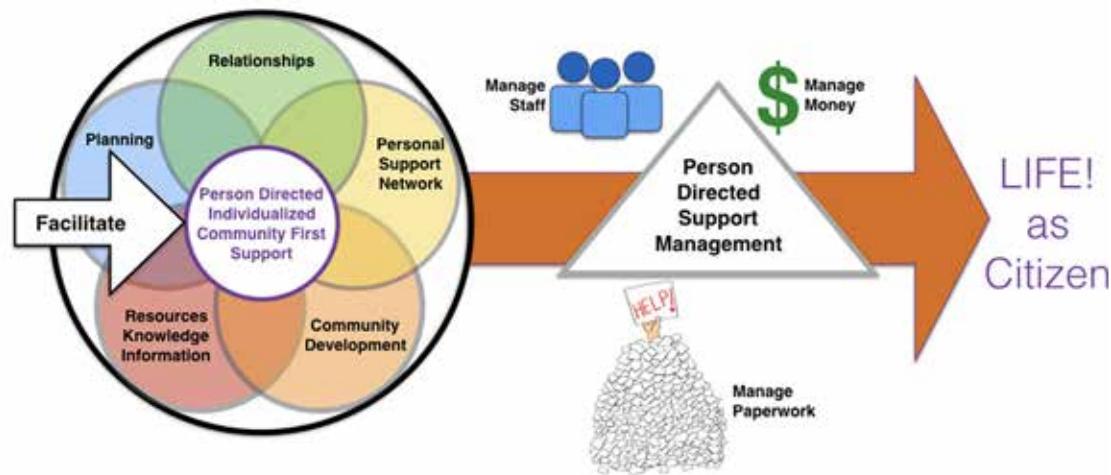
- as a support “relationship” outside of the authority of direct service agencies
- as “someone to turn to” who “walks with people over time”
- to assist people in developing their plans;

- to support people to “make their plans happen”;
- to support people in times of changed circumstances that impact on their need for resources, and the best use of resources available to them
- to support people to stay abreast of government accountability requirements and new resources available
- to support people in negotiating supports and services and the creation of a yearly personal support agreement that sets out mutual responsibilities of individual and service providers

IFOs have used these directives, and other value based best practices shared by experienced Independent Facilitators and knowledgeable resource people as the guide for their work.

the work beyond a person directed plan

In Part C: What Is Independent Facilitation and Who Can Benefit we provide an in depth understanding of the work of Independent Facilitators.



As can be seen in the image above, planning is one component of the work of an Independent Facilitator. It is important to be fully aware of this scope of work, and consider that it is worthy of being funded, rather than to simply offer the development of "a Plan" that people can use to make decisions about how they will utilize individualized funding resources.

INITIAL ENGAGEMENT WITH PEOPLE IN INDEPENDENT FACILITATION

People and families approach the DSO looking for support. The DSO reviews "vacancies" or service offerings that may be available and beneficial to people and their circumstance. The DSO may have more or less knowledge about the offerings available, and the people who are looking for support. The result is that people who approach IFOs in search of support from an Independent Facilitator often arrive not really knowing what Independent Facilitation is and how it can help them.

Facilitators begin the process of getting to know people, and discovering how Facilitation may be able to support their vision and needs. During this initial “getting to know you” period, some people come to a realization that it is not the right thing or the right time for them to engage.

Five hundred and sixty-one hours (561) were spent contacting and/or offering independent facilitation to 205 people who did not qualify as a “service target”. (IFDP Data Overview for Independent Facilitation Organizations). A “service target” as defined for the purpose of the IFDP is the minimum amount of time necessary for people to be engaged with a service, before the service can begin to effectively get paid and meet the number of people expected to be supported through the IFDP. So it is not clear how funding as it exists makes it possible for IFOs to account for this time engaging with people and having beginning conversations which often benefit their thinking about what's possible, even in circumstances where the timing is not right for the person and family to proceed with independent facilitation at this time.

CHOICE AND CONTINUITY OF THE SERVICE OFFERING

For people to be productive and ‘feel right’ and engage with Independent Facilitators, they must enter into a working partnership. There are times where the person who they begin working with does not feel like the “right fit”. People need the opportunity to say this, and then seek the support of another Facilitator. This change takes time and coordination.

People and their families are used to the fact that people who deliver services change, most often for reasons that have nothing to do with them. Service workers and leadership, move, deal with health issues, find new jobs with opportunities for advancement, etc, etc. The challenge facing IFOs is supporting continuity in people's lives when a Facilitator moves on. Who will assist the person and their family in connecting with a new Facilitator, and supporting a meaningful transition to a new person? It does not appear that the funding allocated for Independent Facilitation considers the work involved with addressing these changes and transitions.

OIFN, the IFDP 2017-18 transition year, and beyond

OIFN

OIFN existed before the establishment of the IFDP, and has every intention of existing after the IFDP Transition year. As a provincial network, OIFN has three broad functions related to the practice of Independent Facilitation and Person Directed Individualized Community First Support:

- Sharing knowledge and information: OIFN is positioned to collect and share knowledge, information, and news that can benefit and advance the practice. OIFN will do this through its website; publications; videos; webcasts; and social media. A particular focus is reaching out to the citizen base of people and families, and people who are interested in the practice of Independent Facilitation, to bring clarity to what Independent Facilitation is and who can benefit.
- Convening: OIFN has a history of convening people interested in the practice. OIFN is founded as a Community of Practice, that engages people, families, Facilitators, and allies in dialogue, and shared learning events. OIFN has convened provincial and regional Community of Practice Forums. OIFN has organized the Common Threads Conference in 2014 and 2016. In the upcoming year OIFN intends to gather people from the self-advocacy movement through People First, and the family groups through the Family Alliance of Ontario, and others connected through the Individualized Funding Coalition of Ontario.
- Connecting: OIFNs network makes it possible to connect new people with existing practitioners and with consent, people and families who can share their knowledge and experience. This can be done through direct contact, and online networking vehicles.

IFOs AND THE IFDP COLLABORATIVE

The IFO members of the IFDP Collaborative intend to continue their collaboration in the IFDP Transition Year. The first two years of the Project laid a solid foundation for the work. One Facilitator said, “In a 2 year Project, we are just now beginning to see the fruit of the relationship and trust building, the clarity of people’s vision, and the strength of their families and allies”.

OIFN has provided a strong umbrella to the IFDP Collaborative, ensuring broader strategic learning that helped with more consistent implementation across IFOs. OIFN has acted as a backbone organization, supporting the work of the TPAs for the project to ensure consistent data tracking and reporting.

Most IFO collaborative members have found great value in the ongoing relationship and conversations between other IFOs and the OIFN. Some don’t believe they would have been able to participate in this project without the umbrella role of the OIFN. One IFO lead said:

“The OIFN piece has been huge, particularly around coordination, advocacy, communication with the Ministry. It has been such an all encompassing piece. The learning and problem-solving that has happened at a higher level so I don’t have to do it myself as an IFO, has been significant.”

The IFOs intend to engage in “Impact Learning” together, and cross pollinate experiences, knowledge, and wisdom, that can continue to shape the practice.

a “common cause” collaboration with the ministry

OIFN has always believed that Independent Facilitation is one valuable resource that can assist in addressing challenges that the Ministry faces in serving adult citizens with developmental disabilities across the province.

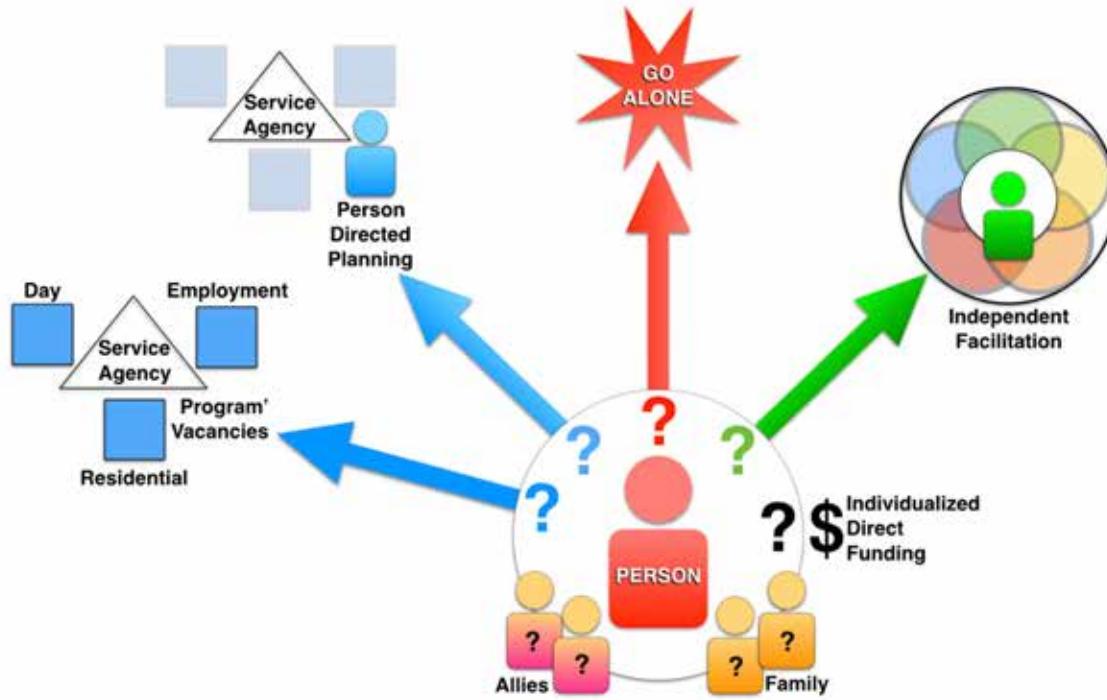
It is our hope and desire for the collaboration with the Ministry to move past the Project phase, that is on a track to end all too soon. There is definitely a desire to ensure that the approximately 1100 people engaging Independent Facilitators do not face the trauma of “start/stop” that so many other people have endured. But beyond that, there is a desire to continue to build the capacity in the province to support Person Directed Individualized Community First Support for more people in more communities.

If the Ministry makes a commitment to expansion, the upcoming year provides a rich opportunity to develop stronger strategies for local “common cause” collaborations with communities who have commitments of people and self advocate groups, family groups, Facilitators, regional MCSS leadership, DSO, and service agency allies.

EXPANDED COLLABORATION TOWARD A COMMON CAUSE

OIFN is not the only network in Ontario who cares about Person Directed Individualized Community First Support. Community Living Ontario’s paper, “Building a Full Life” and a Home of One’s Own in Community through Direct Funding expresses a commitment to people directing their own lives, and establishing home, with individualized direct funding; Community Living Toronto has been studying Individually Funded Services and Supports in Ontario; and the Ministry’s Housing Task Force is tackling the shortage of affordable and accessible housing that can provide alternatives to the traditional agency directed residential programs.

There is too much interest in this radical change to continue working separately.



making options clear for decision making

By the end of 2017-18, 24,000 people receiving Passport funding will no longer face the limited option of fitting into a space or vacancy in a service program, or not. As a result of the Ministry's investment in direct individualized funding, now people will face the opportunities and the challenges of making good choices for using resources that will most benefit their future vision, and their need for support.

Independent Facilitation has survived 20 years of “projects”, as one model that is flexible and responsive to people’s visions, and their need for creating individualized support that can work for them.

Some developmental service agencies are working to develop new models of support that focus on people directing and individualizing support.

Meanwhile developmental service agencies continue to provide agency directed group programs that meet the vision and needs of some people in the province.

However the cost of infrastructure to support these models is far greater than the infrastructure available to people directing the development of individualized support. Apart from the mechanisms that make Passport funding available, there is no infrastructure available and funded by the Ministry to support the effective use of limited Passport funding provided to people and their families.

The coming IFDP Transition year is an opportunity for the Ministry, Independent Facilitation Organizations, and Service Agencies to develop a clear picture of what each of these service offerings can provide as people look to creating the future. People need and deserve to be informed about their options. The DSO needs clarity as they meet the people seeking support.

It is our view that there are distinct differences and benefits that each of these offerings provide. We also believe that expanding choice to meet the unique needs and visions of people makes sense. The Ministry must decide what offerings it is committed to making available, and then clarify what these offerings provide for people and their families.

For more than ten years the Ministry, through Developmental Services Transformation and the Social Inclusion Act, has declared a commitment to make access to support more fair, more equitable, and flexible to meet the individual needs of people in their effort to live as citizens.

The Ministry began this process by making direct individualized funding available to adult citizens with developmental disabilities through Passport funding. However, it is only a beginning.

There is a frightening need for sustainable innovation such that people with developmental disabilities (and their families) can live full lives as contributing citizens.

There are many new potential partnerships of people and organizations that are committed to creating new solutions. There needs to be funding, flexibility and a willingness to learn from our mistakes on the journey to creating the future we all need.

Part E: references

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Taking Social Innovation to Scale: How Does System Change Happen That Works? (2008), D. Frieze, Berkana Institute

Direct Funding and Accountability: What is of Prime Importance? Report from the Ad Hoc Working Group of the Individualized Funding Coalition for Ontario (2010)

Building a Full Life and a Home of One's Own in Community Through Direct Funding (2016), Community Living Ontario

Individually Funded Services and Supports in Ontario (2017), Community Living Toronto

our IFDP learning journey...additional resources

Abundant Community: Awakening the Power of Families and Neighbourhoods

Peter Block and John McKnight.

<http://www.inclusion.com/bkabundantcommunity.html>

John McKnight and Peter Block offer compelling new understanding of how and why community has been lost in our neighbourhoods, cities, and society and what ordinary citizens as well as leaders and professionals can do to restore it. Each neighbourhood has people with the gifts and talents needed to provide for our prosperity and peace of mind — this book offers practical ways to discover them. It reminds us of our power to create a hope-filled life. It assures us that ultimately we can be the architects of the future where we want to live.

Conversations on Citizenship & Person-Centered Work

Edited by John O'Brien & Carol Blessing

<http://www.inclusion.com/bkcitizenship.html>

Conversations about citizenship, community, disability, employment & social change with the developers of approaches to person-centered work: Personal Futures Planning; MAPS & PATH; Person-Centered Thinking Tools; Essential Lifestyle Planning; Cultivating True Livelihood; Framework for Support; Approaches to organizational & community development; Appreciative Inquiry; Asset Based Community Development (ABCD).

Creating Blue Space: Fostering Innovative Support Practices for People with Developmental Disabilities

(Includes downloadable Workbook)

Hanns Meissner; foreword by John O'Brien

<http://www.inclusion.com/bkcreatingbluespace.html>

“Organizations and agencies looking to transform their existing services to more innovative, individualized supports will find a fantastically helpful guide in Creating Blue Space. Powerful exercises and reflections in the book will improve and change how people help individuals with developmental disabilities to have exceptional lives in the community.”

Deepening Community: Finding Joy Together in Chaotic Times

Paul Born, foreword Peter Block

http://www.tamarackcommunity.ca/read?gclid=CKSa_ca3u9MCFZEkgQod6YUJm

Community shapes our identity, quenches our thirst for belonging, and bolsters our physical, mental, emotional, and economic health. In this thoughtful and moving book, Paul Born describes the four pillars of deep community: sharing our stories, taking the time to enjoy one another, taking care of one another, and working together for a better world. It's up to us to create community. Born shows that the opportunity is right in front of us if we have the courage and conviction to pursue it.

Facilitating an Everyday Life: Independent Facilitation and what really matters in a New Story

John Lord, Barbara Leavitt and Charlotte Dingwall

<http://www.inclusion.com/bkfacilitating.html>

"Facilitating an Everyday Life is an invaluable resource that inspires and guides us in the craft of meaningful collaboration, real listening, dialogue, planning and problem-solving. Packed with practical guidelines and compelling examples, yet firmly rooted in the research and principles of self-determination, community connections and capacity building, it is a must read for anyone who loves or supports a person as a family member, friend, facilitator, support circle member, social service worker, or neighborhood leader." Barbara Collier, Augmentative Communication Community Partnerships Canada

Friends and Inclusion: Five Approaches to Building Relationships

Peggy Hutchison & John Lord with Karen Lord

<http://www.inclusion.com/books.html>

It's about relationships! It's that simple and that complex. But that is true for all of us; it takes work to build and sustain friendships. If you happen to experience a disability, building relationships must be even more intentional. It is just a matter of degree. We all need to Belong.

Getting to Maybe: How the World Is Changed

Frances Westley; Brenda Zimmerman; Michael Patton

<https://www.amazon.ca/Getting-Maybe-How-World-Changed/dp/067931444X>

Many of us have a deep desire to make the world around us a better place. But often our good intentions are undermined by the fear that we are so insignificant in the big scheme of things that nothing we can do will actually help feed the world's hungry, fix the damage of a Hurricane Katrina or even get a healthy lunch program up and running in the local school....

Impact: Six Patterns to Spread Your Social Innovation

Al Etmanski

<https://squareup.com/store/aletmanski/item/impact-six-patterns-to-spread-your-social-innovation-1>

Do you want to change the world but feel frustrated by the limited impact you and others have had? Do you feel that despite your best efforts, and indeed successes, you have hit a brick wall? ...Along the way they have observed six deep patterns of change-making which are described in Al's book, Impact. They are keen to share their experience with groups ready to think and act like a movement.

Pathfinders: People with Developmental Disabilities & Their Allies Building Communities That Work Better for Everybody

John O'Brien & Beth Mount

<http://www.inclusion.com/pathfindersbk2.html>

"For a generation John O'Brien & Beth Mount have accompanied people with developmental disabilities, their families and the partners who support them as they find diverse paths to social inclusion and self-direction. These pathfinders' journeys change organizations and build communities that work better for everyone."

Turning to One Another: Simple Conversations to Restore Hope to the Future

Margaret J. Wheatley

<https://www.bkconnection.com/books/title/turning-to-one-another>

Margaret Wheatley proposes that people band together with their colleagues and friends to create the solutions for real social change that are badly needed, both locally and globally. Such change will not come from governments or corporations, she argues, but from the ageless process of thinking together in conversations.

Waddie Welcome and the Beloved Community

Tom Kohler & Susan Earl

<https://www.amazon.com/Waddie-Welcome-Beloved-Community-Kohler/dp/1895418542>

"This is the story of a remarkable man and the people who surrounded him to make their whole community stronger. It is a life lesson in community building from people who became masterful by doing it. It is a treasure story with amazing photos. "The beloved community is not a utopia, but a place where the barriers between people gradually come down and where the citizens make a constant effort to address even the most difficult problems of ordinary people. It is above all else an idealistic community." - Jim Lawson

What Matters: Reflections on Disability, Community and Love

Janice Fialka

<http://www.inclusion.com/whatmattersbk.html>

Janice Fialka is a brilliant writer. Micah Fialka-Feldman is her son. He is a teaching assistant at Syracuse University and one of the most charming people you will ever encounter. This remarkable story draws on the reflections from family and friends and walks us through the journey to this remarkable current reality. But the story begins as a stunning ‘disability’ story except that this family said no. They decided that Micah would be fully included and have a full life. And does he ever.

***What Time Is The 9:40 Bus?* (2014)**

Lucinda Hage, Inclusion for Life; 2nd edition

<http://www.inclusionforlife.com/about>

While this book will appeal strongly to parents of children with developmental disabilities and autism, it is also for family members, neighbours, friends, caregivers, social service workers, doctors, therapists, nurses, educators, and students; anyone who cares about creating communities where every person is seen as valuable.

publications and conference reports from OIFN

Available as downloads from the OIFN Website: <http://www.oifn.ca>

- ***Probing The Edges Of The Work*** (2016)

Facilitators from IFOs involved in the IFDP, explore the edges of the work of Facilitators in assisting people to direct their own lives and find their place in the community, with the support of people who love them.

- ***OIFN Stewards: An Eco-system For Growing Possibilities*** (2016)

The OIFN Stewards envision a network of relationships that make it possible for people with developmental disabilities, with the people who love them, to find their place in the community with support that can work for them.

- ***Reflections on Common Threads 2016: Changing Stories...Stories of Change***

A Conference on Independent facilitation sponsored by the Ontario Independent Facilitation Network, 16-17 November 2016 John O'Brien

- ***Reflections on Common Threads 2014: Approaches and Content for Planning Everyday Lives***

A Conference sponsored by the Ontario Independent Facilitation Network in Partnership with the Individualized Funding Coalition for Ontario. April 2014 John O'Brien

- ***Al Etmanski's keynote presentation:at Common Threads, November 2016***

- ***My Voice, My Choice, My Life Design Evaluation Report*** (September 2009)

Planning Demonstration Project: Independent Planning Model delivered by Windsor-Essex Brokerage for Personal Supports

- ***Common Vision Parts 1 and 2*** (June 2005)

Prepared by Four Provincial Organizations that Represent Families and Individuals with Disabilities: Family Alliance Ontario, Funding Coalition for Ontario, People First of Ontario and Special Services at Home Provincial Coalition

