

# weaving a story of change

The Independent Facilitation Demonstration Project

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

learning so far...

ontario  
independent  
facilitation  
network  
**oifn.ca**



## Part A:

# change, innovation, and the independent facilitation demonstration project

the historical context for independent facilitation	A-1
change and innovation	A-1
a path of innovation	A-2
three big waves of innovation	A-3
• LARGE INSTITUTIONS	A-6
• AGENCY DIRECTED GROUP PROGRAMS IN COMMUNITY SETTINGS	A-8
• PERSON DIRECTED INDIVIDUALIZED SUPPORT	A-10
the origins of the independent facilitation demonstration project (IFDP)	A-14
• THE INDEPENDENT FACILITATION PROJECT LAUNCHED	A-16
independent facilitation organizations participating in the IFDP	A-17
Part A: References	A-18

## 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.mcass.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.

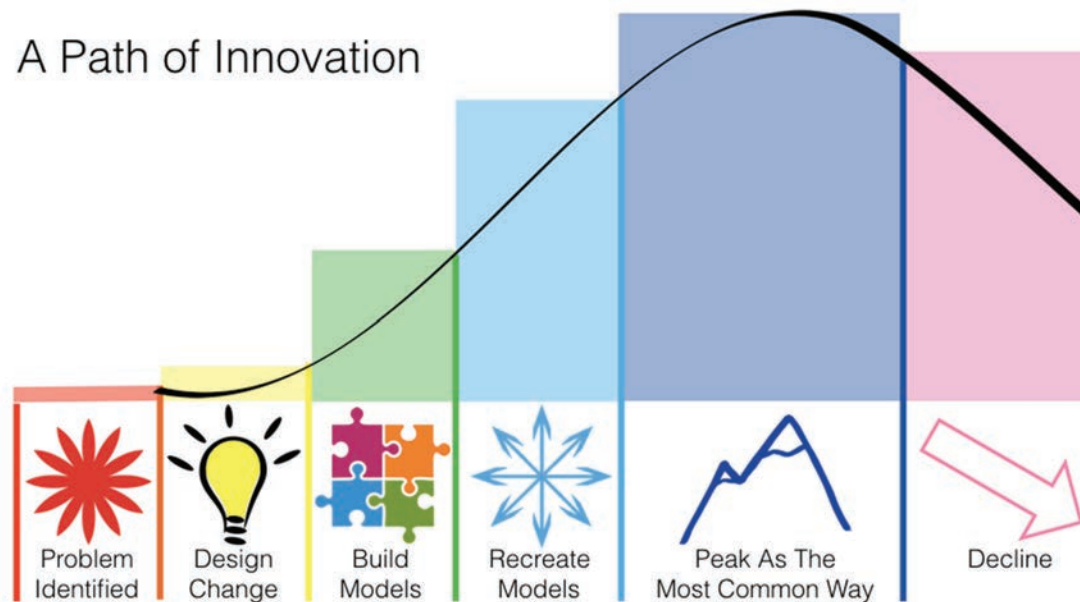
These are the times when we need to **INNOVATE**, meaning “to create change” or “to make something new”.

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, 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.

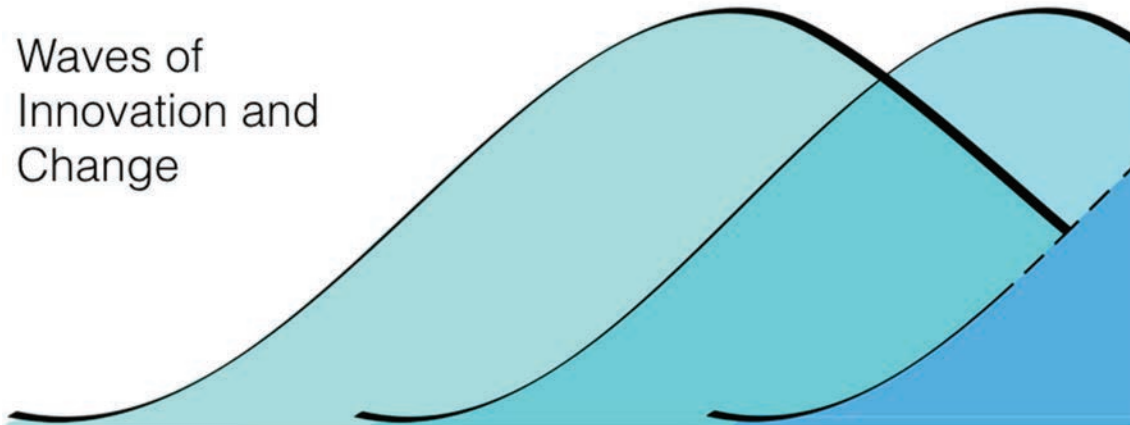
This work is work that local people must do. They must create and design/define “models” (patterns of response) to particular individual and family needs in this place and time. Models can not be ‘duplicated’. They can be re-created and adapted to the differing needs of new people and situations.

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.

### Waves of Innovation and Change



Large Institutions	Group Programs in Community Settings	Person Directed Individualized Support
<ul style="list-style-type: none"> <li>• 1870s to 2009</li> <li>• people were identified as "insane" together with people with mental health issues</li> <li>• institutions created as more humane alternative to jail</li> <li>• Ministry of Health operated "hospital like" settings to:               <ul style="list-style-type: none"> <li>• protect community</li> <li>• treat and "fix" people</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• 1950s to Present</li> <li>• people first labeled with the "R" word</li> <li>• grouped in categories:               <ul style="list-style-type: none"> <li>• educable</li> <li>• trainable</li> <li>• severe to profound</li> </ul> </li> <li>• group programs created for:               <ul style="list-style-type: none"> <li>• school</li> <li>• day activity - life skills, sheltered workshop</li> <li>• residential - mostly group homes</li> </ul> </li> <li>• Ministry of Community and Social Services funded</li> <li>• Agencies directed and managed programs               <ul style="list-style-type: none"> <li>• protect people from community</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• 1980s ...in early development</li> <li>• self advocacy — "We are PEOPLE first!"</li> <li>• inclusive education for ALL children</li> <li>• person centered planning — pay attention to individual person — plan for inclusion in community and school</li> <li>• the Ministry provides direct funding to people and families to create individualized support               <ul style="list-style-type: none"> <li>• SSAH for families (1982)</li> <li>• Passport for adults (2006)</li> </ul> </li> <li>• "Broker" role developed in Windsor and Thunder Bay (mid 1990s) support families to plan and create support separate from agencies               <ul style="list-style-type: none"> <li>• (later to become "Independent Facilitator")</li> </ul> </li> </ul>

"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  
Premier 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 up to \$2500 of their Passport funding to purchase the services of 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 1,100 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](http://oifn.ca)) and seven independent facilitation organizations are working together on this project, which launched in April 2015.

To date the Ministry has not established ongoing infrastructure resources, in particular sustainable funding, The IFDP has been extended for a bridge year and continues 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, jmcgill@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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<https://www.ombudsman.on.ca/Resources/Reports/Nowhere-to-Turn.aspx>

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***2013-14 Annual Report of the Office of the Auditor General of Ontario*** Chapter 3 Section 3.10: Ministry of Community and Social Services - Residential Services for People with Developmental Disabilities