

OIFN Independent Facilitation Demonstration Project

PROBING THE EDGES OF THE WORK



Independent Facilitation: Probing The Edges Of The Work

History

The history of the development of Independent Facilitation was driven by families, self advocates, and allies within the service system. Parents who had led the Inclusive Education movement in the 1980s joined with Self Advocates and parents of adults with developmental disabilities in the 1990s. They came together around advocating for Individualized Funding that would shift the focus of support for people with developmental disabilities, away from congregated services designed to separate and protect, now seeking:

- **CHANGE:** They wanted change in their lives; things to be different; to be growing and moving forward in the direction of their unique desired vision for their lives. People want action to create the changes they want and need.
- **CUSTOMIZED SUPPORT:** They wanted support in their life to be customized to fit their visions and needs. This was in contrast to their experience of a service system that was built on congregated programs, where people who were eligible were expected to “fit into” available spaces.
- **CONTROL:** They wanted to maintain control over their lives, and what happened to them. They wanted to be the ones who directed the course of their lives and the support resources they required to live that life.
- **COMMUNITY INCLUSION:** They wanted to participate; to be in relationship as friend, neighbour, co-worker; to contribute;

to be included as valued members; and experience belonging in the communities where they live.

- **CITIZENSHIP:** They wanted to develop and live as citizens, with the rights and responsibilities that come with citizenship. They wanted to be recognized as citizens first and foremost.

Prior to that period, self advocates and families experienced a loss of control over their lives as they sought support and were provided with services that separated them from community in group homes, day programs, and sheltered employment.

They believed that they needed **support to plan for, and facilitate change in their lives, that would customize their support** focused on making it possible to live as valued community members and citizens, and enabling them to maintain control over their lives and the resources and supports they required to do so.

They believed that this support needed to be **INDEPENDENT** of, and free from the constraints of the existing services that were designed with different purposes in mind, and centered control within the agency.

The facilitation and planning support needed to be **free of any potential conflict of interest** between the authority, design, and control of services, and the person with a disability and their family. Authority and control must remain with the person with a disability, and their trusted family and allies who remain with them throughout their lives.

IFDP

In 2014 OIFN developed a proposal to the Ministry of Community and Social Services to deliver an **Independent Facilitation Demonstration Project (IFDP)** designed to explore what it takes to be able to deliver Independent Facilitation as a service offering that MCSS could make available to people with disabilities and their families in regions and communities across the province.

Seven Independent Facilitation Organizations made proposals to participate in the IFDP as collaborators exploring potentially diverse approaches to offering Independent Facilitation in different communities across Southern Ontario.

Through the Project, the Ministry is seeking to gain an understanding of where Independent Facilitation fits within the array of developmental service offerings that are funded by MCSS.

Throughout the Project, Independent Facilitation has been aligned and associated with the Ministry offering of Person Directed Planning (PDP). PDP can be offered by agencies delivering developmental services, or by Independent Facilitators not associated with service agencies. From a Ministry perspective, it appears the only distinction is that Independent Facilitation is Person Directed Planning that operates outside of an agency that offers direct support services for people with developmental disabilities.

For Independent Facilitators and IFOs however, while they engage in guiding Person Directed Planning, they have identified “facilitation” as more than “planning” as it has

become known. Facilitation is an ongoing relationship of “walking with people”, assisting them in developing the life of community and citizenship they seek.

Probing The Edges Of The Work

In an effort to gain clarity about how Independent Facilitation is distinct or different from other PDP offerings, Facilitators within 6 of the IFOs engaged in an exercise to look at 4 things:

- what issues of CHANGE do people present that **Independent Facilitators** feel they can do something about?
 - what are the action responses to those things?
- what issues of CHANGE do people present that **Facilitators** feel they don't do something about?
 - what are the action responses to these things?

The Core: Facilitating Change

The core commonality of the issues presented by people with developmental disabilities and their families, is that they are all seeking CHANGE. They all want something to be different then it is now. Facilitators envision their work as walking with people as they create the change they want to see.

They want to DO something to CHANGE the way things are now.

What follows is a summary of the kinds of things people want to change, and the kinds of actions Facilitators engage in response to make it possible for this change to happen.

CHANGE Issues

Strengthen Voice and Vision

People want and need to be heard. They want to be able to communicate what is important to them and have other people hear and respect what they are saying.

They want to be able to make things happen in their life; to discover what is important to them, and do something about that; to be actively involved in creating their own unique lives, instead of living with the consequence of other people's decisions.

Supporting people to develop their vision, the voice to communicate it, and the power to act on it, is at the heart of what Facilitation is all about.

Life Planning

Many people are looking to develop more comprehensive plans; to clarify their vision; to articulate the outcomes they want to achieve; identify the resources that can assist them; plan for actions that will move them toward achieving what they set out to accomplish.

Transition Plans: People find themselves in periods of transitions — leaving school; moving out of their family home; getting married; moving to a new community...etc.

Meaningful Life: There are people who are just not happy with the way things are now. They want life to be full, to have things to do; to have meaning, to feel good about themselves and their lives.

“Legacy” Planning: Families often have great concern about what life and support will look like for their family member if they were not around. They want to be proactive and put things in place for when they will no longer be there.

Estate Planning: Families want to plan to ensure that there are financial resources and assets that will be available to support the life of their family member.

Daily Life Basics

People want to make changes to the basics of daily life:

Home: As adults, many people want a place of their own, beyond their family home. They want to choose who they live with, or if they will live by themselves.

Finances: People want to have, and be in control of, money for their personal use. There is also a need for funding that can be used to hire direct support staff, to purchase necessary equipment, to access housing that is accessible, and more.

Direct Support: Many people need direct support to do things; go to places; to make and sustain connections; to work, etc.. People have been, and can be, supported by people (family, friends, etc.) who are not paid. But often they need people who can be paid to accompany and provide support. As people become clear about the things they want and need to do, they also identify the kinds of things they need support for, when they need it, and how they need it to be done. They are looking for how they can get, direct, and maintain that support, whether it is paid or non-paid.

Transportation: As people identify what they want to do, and where, they need to figure

out ways that they can get around so they can show up, develop relationships, contribute, work, etc.. They need to figure how ways of getting around can work when they need it, can be accessible if they need that, and affordable.

Time: There are 168 hours in a week. A very large percentage of people with disabilities are unemployed, or at least significantly underemployed. They are faced with the challenge of figuring out how spend the time that is available in ways that build the life they want to live.

Learning and Interests

When people are not employed, pursuing learning and interests are ways to continue to grow, develop, become more skilled, build capacity, meet new people who can become friends, or simply expand the network of people who they know, and who know them.

Education: As adults, there are many people who want to continue their education, go to college or university; get their GED; to develop literacy skills; to attend classes for things they are interested in, such as hobbies; to develop skills.

Groups: People are looking to find people to spend time with who share common interests in: faith communities; the arts; sports; fitness; hobbies, and a host of other possibilities. They might be looking for one time experiences, or searching for ongoing connections.

Activities: People are looking for things to do, opportunities to explore. It could be walking in a 5 km event, attending concerts, local and professional sporting events, festivals, hiking, cycling, etc.. These activities are opportunities to participate and be active in things they already enjoy, or chances to

expand experiences and try things that are new.

Places: Getting to know places where people gather. Places where people can show up and become “regulars”; where they get to know the people who go there regularly, and become known over time.

Work

By far, people with developmental disabilities are among the most unemployed or underemployed people in our country. As a result, they are most likely to be poor. They are also more likely to experience the side effects of unemployment and underemployment...depression, and issues related to self-worth. Working is a vital source of worth, practically, socially, emotionally, and spiritually.

Employment: There are many people who are looking for a job for which they get paid a fair wage. They want to earn a living. They want to explore work that uses the skills and capacities that they have, and provides opportunities to develop new skills. They want the opportunity to look for work that provides the opportunity to advance. Many would like to have a career.

Volunteering: There are people who are looking for work that allows them to make a difference in other people's lives, and in their community, or the world. They want to contribute in ways that are valued by others; they want the opportunity to be needed.

Small Business: There are other people who are interested in the creativity, and autonomy of running their own business. The chance to turn something that they know how to do into an opportunity to earn money, where they are in charge and responsible.

Relationships

Relationships are central to being human. We are social beings. The treatment of people with developmental disabilities as “incapable”, “special”, “vulnerable”, and in need of protection from the broader community, placing people in congregated and segregated education, housing, and service programs, has resulted in a systematic breakdown and disconnection from relationships.

People deeply desire to be in relationship, to develop their ability to be in relationship, to contribute and receive the value that comes from being in relationship.

Friends: By the time people have become adults, many are seeking to develop relationships with people who are beyond their family; people they can spend time with and do things together; people they can support and be supported by; people they can trust, and love. They are looking for ways to find and keep friends.

Family: As adults, people are looking to have their relationship with parents and family, grow and change. They want to be respected; to have more authority and responsibility for their lives; to be allowed to try, fail, and try again. They are looking for ways to make their voice, vision, and desires known and respected by their family. They are looking for support when their vision and desire are in conflict with their family and/or guardians.

Intimacy and sex: Many people are seeking to expand and deepen their experiences with intimacy and sex. They are wanting and needing experience, in ways that increase the probability that they will be safe and healthy. They are looking for advice, guidance, and support to explore this aspect of their lives.

Love, Marriage, and Parenting: As people with developmental disabilities age and develop, they desire many of the same things that the rest of the adult population desires... love (boyfriend/girlfriend), marriage, and creating family. They are looking for support to experiences, and to be supported when these relationships have conflict, change, breakup, fall apart.

Support Circles: Many people looking for a group of people who can be “my people”, the people who support them as they face the challenges that come with acting on their visions. They are looking for people who can listen to their vision; help them think and plan; accompany them as they act upon what is important; and learn together.

Health

People with developmental disabilities experience a full range of issues that are related to health. These issues can be complicated by the prejudice and the historical segregation of people. Community health providers may have limited experience supporting people to prevent health crises, and treating them when they are experiencing health crises.

Physical Health: People, with their families, often seek support and guidance when they have to access the health care system, particularly when they: transition from pediatric care to adult care or move to a new community. People look for support to be proactive about their health as well as responding and getting appropriate care when a health issue arises.

Undiagnosed physical health issues often are the source of issues that present as behavior challenges that can lead to dangerous experiences, risk of physical harm, and even

engagement with the police and the legal system.

Strategies for sorting out issues related to communication with medical professionals is often needed.

Mental Health: Finding mental health professionals willing and capable of receiving and treating people with developmental disabilities is often a profound challenge.

Health Crises: People, with their families, often need support to figure out how to address life changes that occur when health crises arise, including things such as direct support needs; family support, and many issues unique to their circumstance.

Systems

People face overwhelming confusion and frustration as a result of seeking support through so many systems: Developmental Service; Housing; Medical Health; Mental Health; ODSP. They look for support to assist them in getting what they need to make the changes they envision.

Navigation: Often people need support to figure where to go, who to speak with, and how to present their concern so that it will be recognized and understood by the system they approach.

Funding: Many times, the resources they require to support their life (housing, staff, equipment, modifications) require financial resources beyond personal and family income and assets.

Services: When people engage with services, they often seek support and strategies for ensuring that their voices are heard, and support can be customized to meet their unique needs and desires.

Facilitating CHANGE

There is a wide range of change issues that people need to act on. The experiences that people have had to date have been profoundly challenging, and often traumatic. The work of facilitating change requires meeting and understanding where people are at, and where they have been.

While the work of facilitating change can involve “person directed planning” as it has become known, more often it involves smaller plans, followed by action, and then reflecting on learning, in order to figure out the next thing to do that will build upon the last action.

An Ongoing Relationship

It is this practice of small, “micro-planning”, that makes it possible for people to try, experience success or failure, learn from the experience, and build capacity and confidence to actually direct their own lives.

For this reason, Facilitation is an ongoing relationship, walking with people, assisting them with plans, actions, the experiences that result, and cycle of learning.

The alliance of the Facilitator rests with the person, and their trusted family members. It is a relationship that is designed to support the capacity of people to direct their own lives.

The basics in this ongoing working relationship of facilitation are:

Listening: Deep listening, with a genuine intent and desire to understand who this person is, and what they truly desire and need, is at the core of the work.

Communicating with the person in ways that lets them know that they have been heard and understood.

Building Trust: Developing a relationship with the person that lets the person know and experience that we are “on their side”. It involves deep listening, and communication, but it also involves actions that align with what the person has expressed as important. It involves follow through, doing what we say we will do.

Prioritizing: Since there are so many issues that people need and want to change, the work of facilitation involves helping people to make decisions about what is important to do FIRST, given the vision they have expressed, the needs that are most urgent, and the resources of people, money, and time that are available.

Planning: The work involves planning for ACTION — making decisions about WHAT we will do; WHO will do it; and WHEN it will be done.

Action: The work involves making sure that people FOLLOW THROUGH on plans that have been made. It involves Facilitators following through on what they have said they will do, but it also involves finding out what other people will need to be able to follow through.

Reflection and learning: Facilitators support the learning that can come from experience, making each plan and action build on the capacity of people to be stronger, more powerful, and more capable of directing their lives. Facilitators guide a process of reflection for the person and their trusted circle of support, with the intention of learning that can guide future plans and action.

Things Facilitators DO:

Inquiry and Dialogue: Facilitators engage in an ongoing process of inquiry, asking questions, with the sole purpose of understanding the

person’s experience and what people are saying about what is important to them.

Gather A Support Circle: Facilitators help people, and their family, identify who “their people” are. Who are the people that have been and can be supportive? Who are the people who care about what happens to them? They help people to invite this trusted circle to come together to think, plan, act, learn, and celebrate the ongoing journey to create changes in their lives.

Facilitate Planning Processes: For over 30 years person directed/centered planning processes (MAPS, PATH, ELP, Personal Futures Planning, and more) have been developed to support people and their trusted allies in creating changes that lead to community inclusion and citizenship. Facilitators utilize these processes when appropriate.

Facilitate Reflective Learning: As people make plans and follow through with action, Facilitators guide them in learning from the experiences that result from the actions, within the intent of continuing the process of planning and action that generates clarity about what they want and what needs to be done next.

Research Available Resources: Planning involves identifying the resources necessary to fulfilling the plans. Facilitators research community and government resources that can be available to move plans forward.

Provide Information: Facilitators gather and offer information that can assist them in their decision making, and guide their actions.

Connect To Resources: Facilitators let people know what will be involved in making connections to resources that can assist them in making the changes they seek. They

let people know what is required, where they should go, and who they can contact.

Accompany People For Initial Contact: Facilitators often accompany people as they make initial contact with people and places that can move them forward. They can coach and guide people in learning how to make these contacts, how to learn about the culture of places and people they want to be connected with.

Facilitate Problem Solving: Facilitators assist people and their allies with problem solving when things do not turn out as they had hoped or planned, or when unexpected challenges and circumstances arise.

Prepare for...: Often people’s plans require steps that they, or their family, have very little experience with. Examples can be: writing proposals for funding for housing or services; developing job descriptions for Direct Support Staff or Job Coaches; interviewing potential staff or housemates; interviewing for a job or volunteer position; attending meetings with government officials, etc.. Facilitators can assist people in preparing for these new experiences.

Coach and Advise: Facilitators can become someone who the person, or their family, can turn to and seek advice when developing their plans and actions.

Facilitate Mediation and Dialogue: As people move forward with their vision and plans, it is not uncommon for them to experience conflict with other essential supporters, sometimes family members or guardians; service providers; direct support staff; funding agencies; health providers, etc. Facilitators may engage in supporting people in making their vision, needs, and experiences heard, by facilitating conversations intended to mediate and increase understanding through dialogue.

Things Facilitators DON'T DO:

It is important for people and their families to understand that there are things that Facilitators do not do:

Case Management: Facilitators do not have role in referring, assigning, coordinating, or monitoring services.

Respite: Facilitators do not do “respite”, spending time with people so that their families can “have a break”.

Personal Attendant Care: When accompanying or spending time with the people that they support, Facilitators do not take on the role of personal care attendant.

Ongoing Transportation: While Facilitators may accompany people to places, meetings, and experiences on occasion, they do not provide ongoing transportation.

Ongoing Direct Support: Facilitators do not provide ongoing Direct Support required for daily life.

Mitigating Factors

The ongoing relationship of Facilitation is based on the person directing their own lives. There are some factors have a significant impact on the capacity of people to do this.

Individualized Funding Available: The person may require funding resources that are not available: to hire direct support workers; access equipment; rent or purchase housing; renovate for accessibility.

Resource Eligibility: People may not have been able to demonstrate eligibility for resources that are necessary to move forward with support; or they may be low on a waiting list.

Accessible and Affordable Housing: The supply of accessible and affordable housing is a challenge for most people, and some locales possess greater challenges than others.

Family/Guardian Vision and Relationship: Family members and designated guardians often possess a significant amount of authority and power in the lives of people with developmental disabilities. It is not uncommon for the vision and plans of the person with a developmental disability to be in conflict with the vision and plans of the family or guardian. This conflict may be a difference in view about what is best, or it may be more fundamental with family or guardian believing that the person does not have the capacity to imagine and direct their own life.

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