

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
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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.

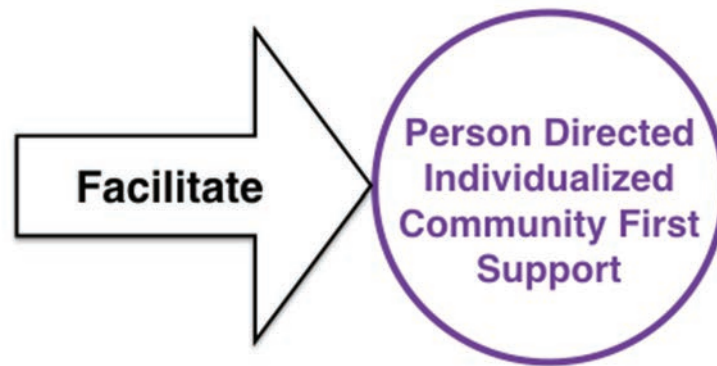
person directed individualized community-first support

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 citizens. 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 been 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 to 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 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,

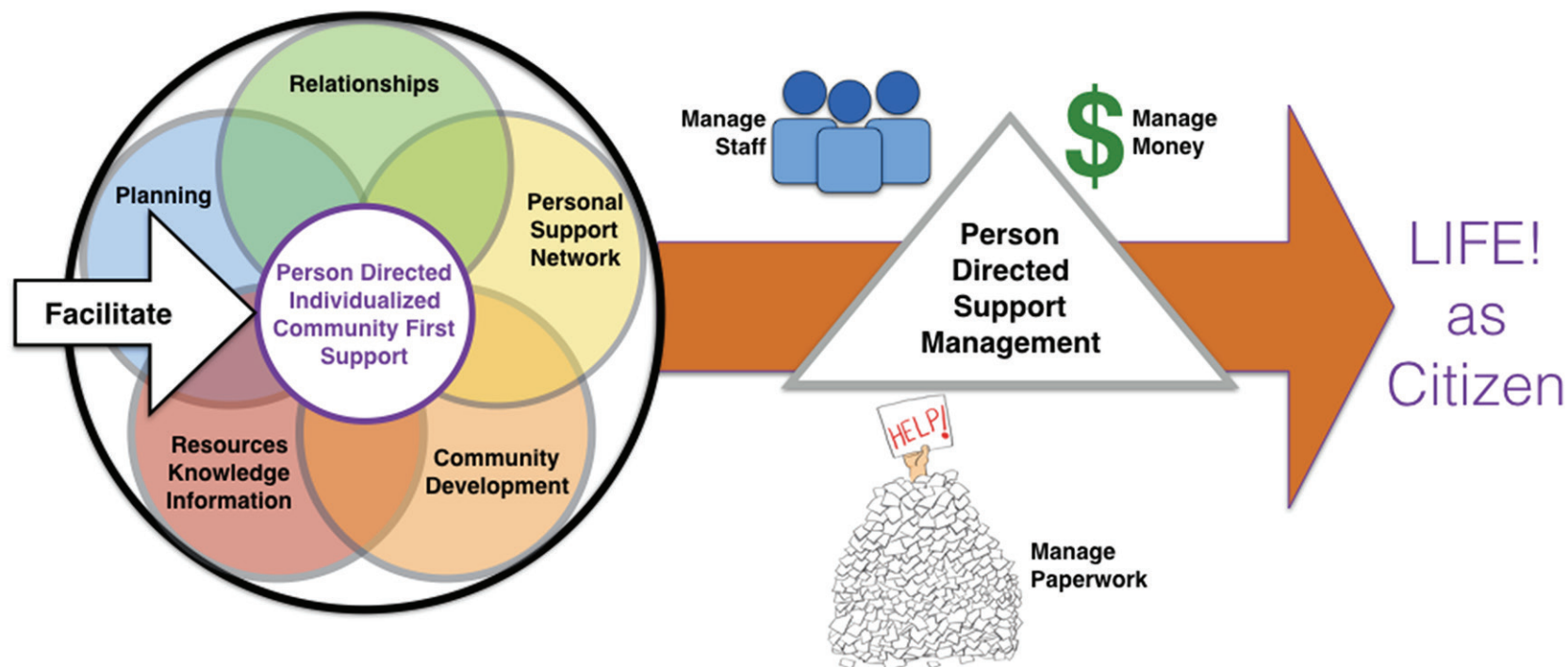
Beth was already familiar with the dance group, so Judy just helped her to sort a way that she could get to the dances.

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.”

For everything there
is a season, and a time
for every purpose
under heaven
Ecclesiastes 3:1-8

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

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 know 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 activities. 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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