

# weaving a story of change

The Independent Facilitation Demonstration Project

**Part B:**  
what people say they want and need

learning so far...

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network  
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## Part B:

### What People Say They Want and Need

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## community gatherings

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

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

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

The groups had conversations that explored:

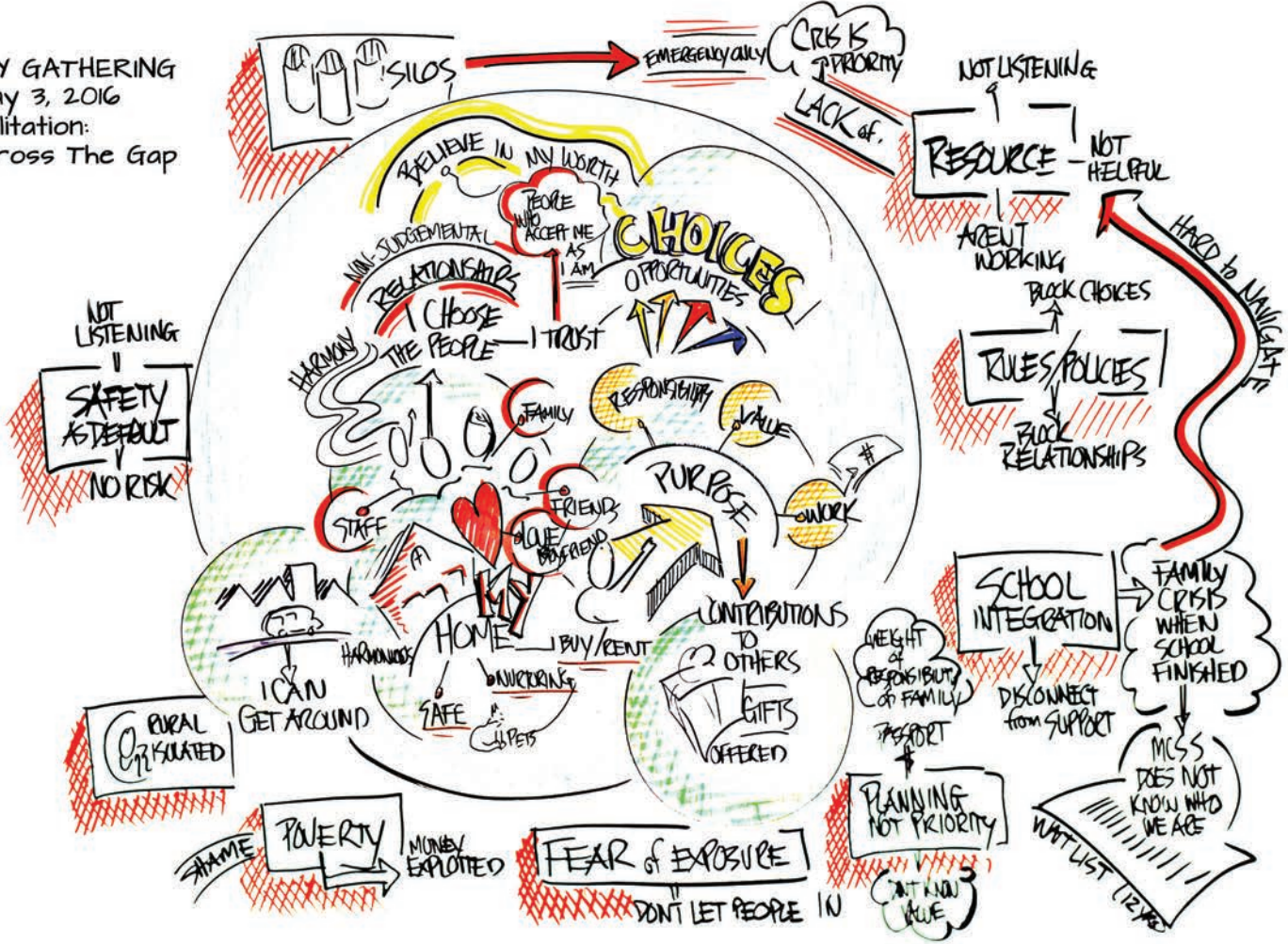
- *What would a good life look like?*
- *What is life like now?*
- *The role of Independent Facilitation in bridging the gap between now and the future people need and want.*

They summarized their Good Life aspirations into seven topics:

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

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

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



## what would a good life look like?

### HOME

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

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

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



## RELATIONSHIPS

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



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

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

## CHOICE and CONTROL

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

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



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

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

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

### PURPOSE

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

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

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

### WORK

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

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

### VALUED SENSE OF SELF

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



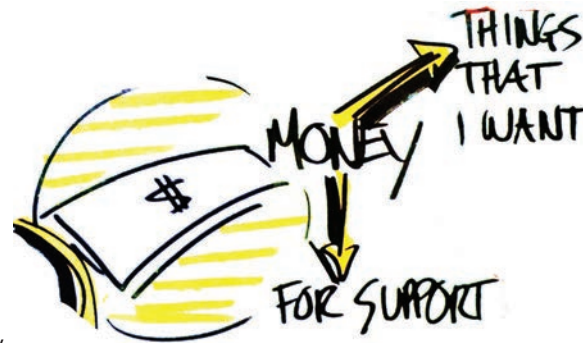


People want to be heard. They want to know that what they think, say, and do is important. People want to speak up and use their voice to communicate. They want to be taken seriously.

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

## MONEY

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



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

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

## what is life like now?

### *What we heard at the Community Gatherings*

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

#### **THE GREAT BLACK HOLE WHEN SCHOOL IS OVER**

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

#### **THE CONFUSING MAZE WHEN LOOKING FOR SUPPORT**

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

#### **A HARMFUL NEGATIVE FOCUS**

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

## **NOT BEING HEARD**

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

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

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

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

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

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

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

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

## **COMMUNITY EXPECTATION and LACK of EXPECTATION**

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

## **RULES, POLICIES, and PRACTICES THAT GET IN THE WAY**

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

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

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

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

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

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

## **POVERTY and LACK OF SUPPORT FUNDING**

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

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

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

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

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

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

## **PLANNING IS NOT A PRIORITY**

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

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

**LACK OF RESOURCES...north and rural**

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

## “nowhere to turn”

### The Ontario Ombudsman Report

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

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

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

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

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

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

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

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

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

## independent facilitators — “SOMEONE TO TURN TO”

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

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

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



## Part B: references

***Hamilton and Niagara Region Community Gathering***  
(2016) OIFN, Independent Facilitation Demonstration Project

***Kingston and Area Community Gathering*** (2016) OIFN,  
Independent Facilitation Demonstration Project

***Thunder Bay Community Gathering*** (2016) OIFN,  
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***London and Area Community Gathering*** (2016) OIFN,  
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***Nowhere To Turn: Investigation into the Ministry of  
Community and Social Services' response to situations  
of crisis involving adults with developmental disabilities***  
(2016),  
Ombudsman Ontario  
<https://www.ombudsman.on.ca/Resources/Reports/No-where-to-Turn.aspx>