

# weaving a story of change

The Independent Facilitation Demonstration Project

**Part D:**  
**the challenge of getting started**

learning so far...

ontario  
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## emerging communities working to make independent facilitation possible

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

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

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

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

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

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

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

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

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

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

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

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

There are some particular challenges:

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

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

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

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

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



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

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

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

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

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

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

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

## historical context challenges

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

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

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

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

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

*(Ontario Ministry of Community and Social Services (1994)*

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



## start/stop “project” challenges

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

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

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

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

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

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

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

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

“who cares?”

## an eco-system of relationships for succesful innovation

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

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

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

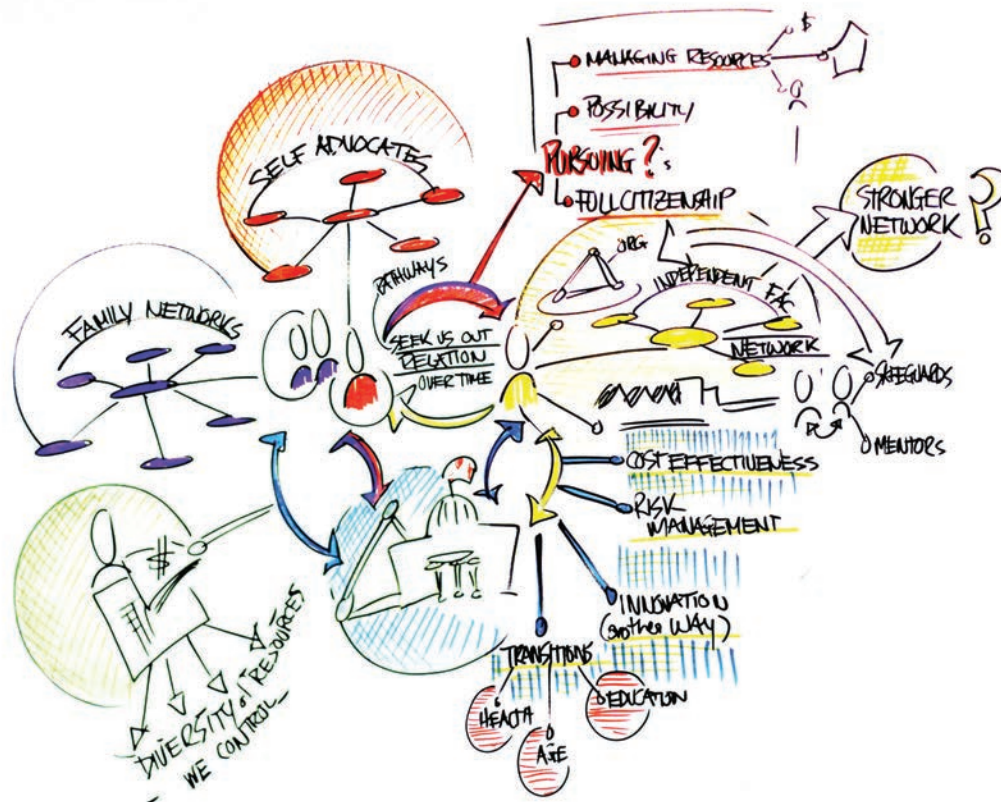
*Windsor-Essex Brokerage  
Pilot Project Evaluation Report  
The Roeher Institute 1998*

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

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

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

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



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

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



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

### **SELF ADVOCACY GROUPS AND NETWORKS**

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

### **FAMILY GROUPS AND NETWORKS**

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

### **INDEPENDENT FACILITATION NETWORKS AND COMMUNITY OF PRACTICE**

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

### **MINISTRY ALLIES AND RESOURCES**

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

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

### **SERVICE AGENCY ALLIES**

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

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

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

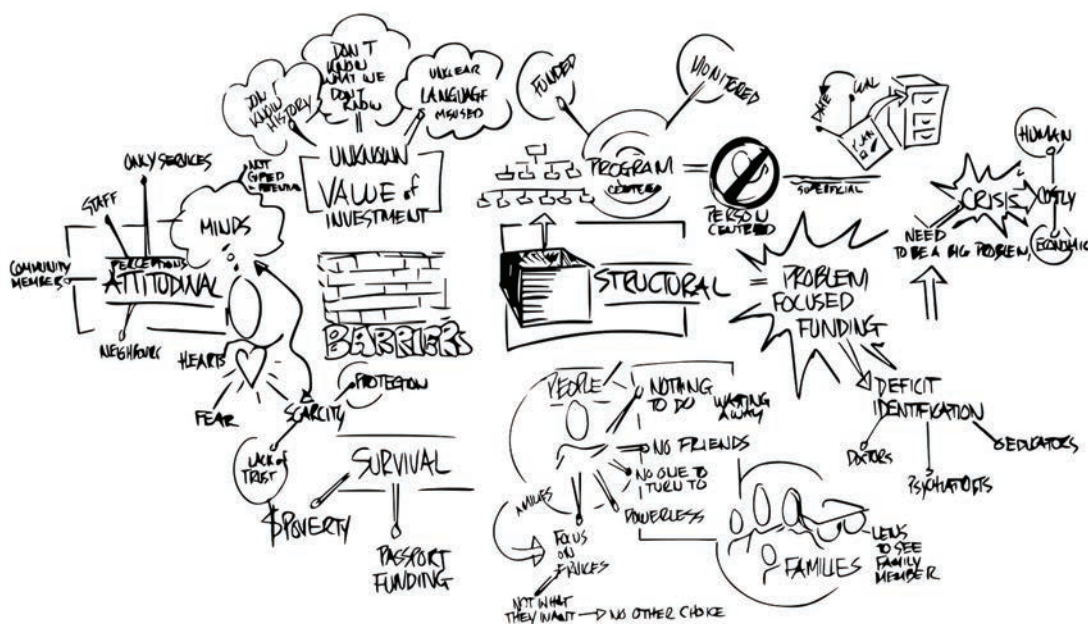
### **WE ARE EITHER WORKING TOGETHER OR WE ARE WORKING AGAINST EACH OTHER**

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

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

## thunder bay insights and analysis

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



## ATTITUDES-- HEARTS AND MINDS CHALLENGES

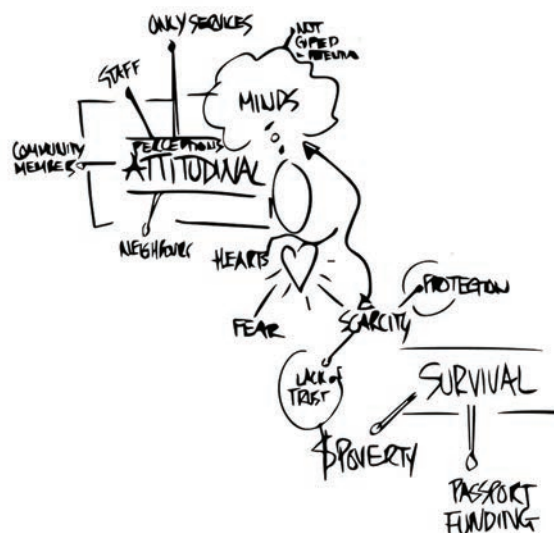
Our attitudes are shaped by what we see and experience.

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

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

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

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



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

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

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

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

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

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

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

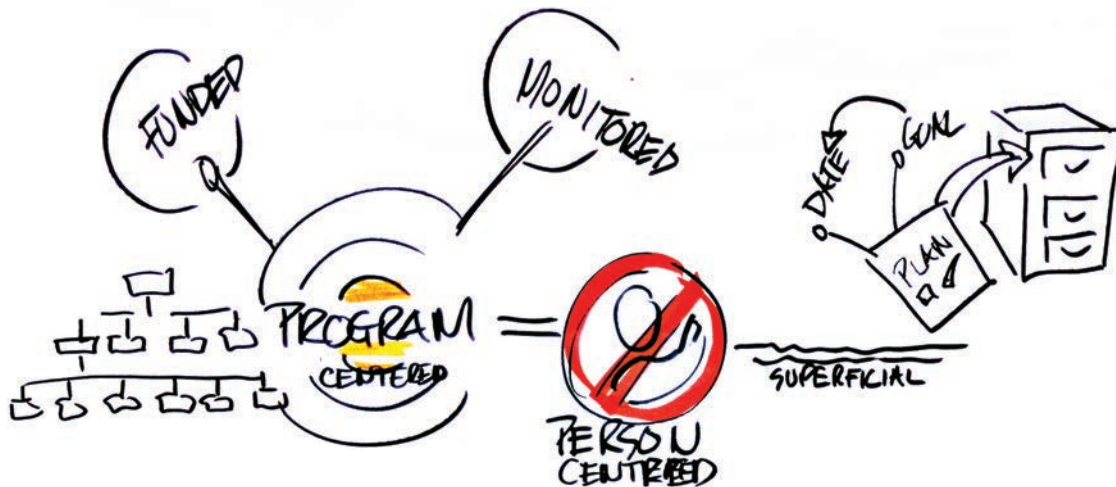


## STRUCTURAL CHALLENGES

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

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

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



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

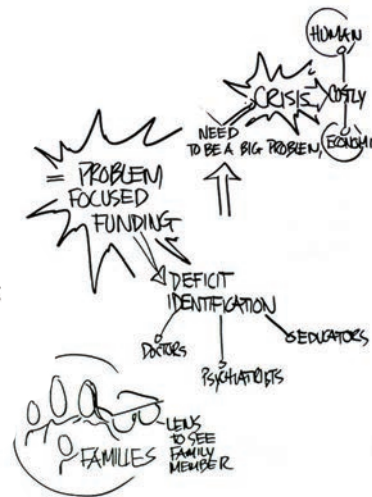
They have established “person centered plans” as a means of keeping track of this monitoring. The plans are annualized, and are tracked for when they happened, who attended, what goals were identified. They are then put into a filing cabinet, in case somebody needs to follow up later, usually because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

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

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

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

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



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

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

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

## PRACTICAL CHALLENGES

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

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

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

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

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

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

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