



## **OIFN Summary of Family Gatherings Insights and Impact Report October 18, 2017**

***“A gift is not a gift unless it is shared”  
- John McKnight***

### **Background**

In 2015, seven Independent Facilitation organizations across the province received funding through the Independent Facilitation Demonstration Project (IFDP). As of March 31, 2017, 1091 people with developmental disabilities and their families and/or loved ones have received independent facilitation support through this project.

Over the past two months, OIFN co-sponsored twelve family gatherings across the province. Each of the seven Independent Facilitation Organizations (IFOs) took responsibility for hosting these family gatherings in their communities. Because some IFOs provide Independent Facilitation in large geographic regions, some organizations hosted multiple events to create opportunities for people and families from various communities to attend.

### **Goal of Family Gatherings**

- **To listen to the stories of people and families to learn how Independent Facilitation has impacted their lives.**
- **To gather key messages and insights about the nature of Independent Facilitation from people and families.**
- **To learn from people and families what it has meant to them to have the support of an Independent Facilitator and how it is different from other supports they receive.**
- **To better understand what people and families need as they take on changes in their lives and how we can serve them better.**
- **For people and families to identify what is needed - assistance with recruitment, hiring/contracting with paid people (service provision), independent facilitation, advocacy, direct individualized funding that is more than \$35,000.00.**

## Goal #1: To listen to the stories of people and families to learn how Independent Facilitation has impacted their lives.

People and families reflected on what has changed, as a result of having Independent Facilitation Support. The Key messages/quotes from people and families are organized below into themes. Some themes are followed by longer reflections; these stories shared by people and families speak powerfully about the main benefits and outcomes of Independent Facilitation.

- **People and families feel supported**

- Continued support is provided
- Support has been long term
- Support is flexible
- They are always ready and there for my daughter
- It is empowering
- Facilitators never give up

- *We owe a lot to our facilitator as there were sensitive matters that was hard to discuss with my son, most of the time my son didn't want me to go with him but he's ok with her to be there. I remember one incident when we went to Ontario Works to learn whether he can be helped. He got upset, he said he didn't need any help. We went home, with no result and both upset. I cried in the car out of desperation. I missed my work that day and with no result. Then the Facilitator helped him with his ODSP and it got approved. He became independent, he goes out to buy his own things. He was able to go back to Centennial after being on probation because he failed most of his courses before. His Facilitator mediated between college and him. He now can continue his Computer and Repair Maintenance Program.*
- *The Facilitator didn't give up – they kept trying over and over and things began to change.*

- **A sense of confidence and hope is created**

- The work is reassuring
- Hope for ongoing work as life changes
- Hope for son's future - to be more independent and less dependent on family
- Forces us to think about their future

- *I will say about entering into this organization. Once I graduated from elementary to high school, I got interested in computers and computer technologies. I am fond of electronics and computer hardware. I was shut down, no motives. No motivation. I was like grounded. Until my Facilitator came by along with my parents, I got a glimpse of hope. A fire that has been re-kindled. Re-kindled fire is starting to blaze. When you add fire logs into the camp fire, the flame is starting to blaze upright. I was like that. What I notice about the organization, it's my very time that I find some redemption from my own failures. For once, I want to achieve something big. Something larger because I was very ambitious back then since college. When I saw my failing marks from college, it was a shell shock for me. I felt very pretty much dead. Bluntly to say. I spent most of my time, years wandering around. As if I was smoke that's been exhausted. But now, my confidence came back. Re-ignited. With support of an Independent Facilitator, I learned something about between being hopeful and being hopeless. First, I will say hopeless - sorry for being gloomy - when I failed at college, I was given to disparity. Very saddening. Wished I could cry but I couldn't cry. I wish I was. Only my heart does the crying. When it comes to hope - I see a glimpse of light within the darkness. It really shined down as the very dark of disparity - I began to climb out. I felt like to take charge of my own fate. But it wasn't fate though I was thinking about. But rather ... I found a new purpose. I thought about it a long time. When I heard about the organization. I began to realize that one day I will climb something higher. Something larger. I want to be a bit ambitious. Not too much. Confident but not over confident. Life has been zeros*

*and ones. Not every life has been perfect. Not every life has a great design. Some could be large. Sometimes could be small. Even though my life was somewhat great, but same time was something poor. I went back to school to Centennial College. Thinking of metaphors. I was very eager. I had my 2nd chance to enroll back to college. School of computer technology. It is a very amazing program. I want something to satisfy me as a person - something that is me, that recognizes me not as an autistic person who has this disability and drawbacks - but to recognize me as a person who can overcome these drawbacks. I always wanted to achieve something. Want to say to myself... although my life was hinge of inside downs and sometimes being gloomy and depressed, when there's that dark of despair, there's always a light of courage.*

- *It helped my son to begin climbing out of his depression.*
- *It gave my son courage.*
- *It reignited his interest in his education.*
- *For many years, there were never smiles from my son, now there is.*
- *We had no one before our Facilitator came. She helps guide my daughter. Independent facilitation enables the individual to be an adult, and build self-esteem and self-respect.*
- *We are blessed with 3 kids with disabilities. Our lives were fragile until I found the help. Our Facilitator started helping us and built confidence with my daughter. People live with it. Abnormality. Some kids are so gifted, there is no help - in my country there's no help...in Canada, I'm very proud to be here. The Facilitator helps my daughter in building self-confidence and how to deal with the wonderful world. She supports us and makes life easier. Sometimes my daughter gets angry at me because her brothers don't have to clean up and she does and so she says she's going to call the Facilitator.*

- **Son/daughter has a stronger voice**
  - My son/daughter has a voice
  - We are learning more about our son/daughter
  - Communication is open and direct
  - Discuss items by writing out things
  - Has helped her see she can direct and take the reins, more structured focused pride in myself, focusing, got a phone "duoingo" learning new languages,
  - Ability to process his feeling
  - Have become stubbornner about what he wants to do and say, more outgoing,
  - Able to control direct and create, where others have not been able to elsewhere in province
  - My son's participation in the process was progress
  - Our daughter is more open at the meeting with the facilitator
  - Something just for "her"
  - Continual growth in confidence

- *I want to write a book about my life. With my Facilitators support I have ideas and an outline - what stories need to be included. My mother is here today. I want her to see other people with disabilities and their lives. I don't know what kept me strong. Courage through it. A smile. I want a good life.*
- *My brother is changing - when he wants something, he says "I need help" he speaks more. Tells me what he wants. More open. More understandable, communication. He's good. He is funny and he is supportive sometimes. Happier. More self-sufficient. He's a very nice guy. Talented.*
- *We had a one day planning day and you share stories like we are doing today. I think we should all have a planning day - whether we have a disability or not. It is a long day however I had I*

*never thought of my daughter that way. I had never thought of this aspect of her. Now - My mother-in-law carries photos of my daughter's paintings. It has created a whole network of family members. We are learning how to see her as a contributing member in her own life. The person who is creating her own future. We have a whole network of people who are telling others who she is and what her gifts are. If you do this you will meet others you never thought you'd meet because you now have a team working for you.*

- *It helps us understand their talents better.*

- **Thinking of possibilities, options, and more opportunities**

- Ideas about the future we didn't think was possible
- We have a PATH to keep us on track
- Helps with balance and possibilities
- Open your eyes to what is outside, options I can do more in the community, don't have to follow agency rules, have more opportunities
- Getting more involved with community, my son is participating more than I anticipated
- Volunteering
- New goals/dreams
- Find out information about what interests my son
- Discussion of possibilities we didn't think existed, involved in community
- Practical practice to do job interview
- Make us know there is a light at the end of the tunnel
- Son is out-going now - plays music

- *My daughter literally sang before she spoke. From an early age, her love of music became a connection and a bond with others. Born into the realm of autism with little language to communicate in her early years, her music became her voice. For a very long time, one of her dreams was to sing with a full Orchestra. She can sing Judy Garland like nobody can. As a mom, we need people to do the big ask, It's not right and feels funny for me to do that for my daughter. Her facilitator, contacted the Executive Director for the Orchestra and basically said, 'I got an idea'. That led to several conversations to figure out how this could happen. She now will be singing with the Orchestra. My daughter says this is unbelievable, and something I have always wanted to do". It is time to celebrate who we are without any discrimination. This is my choice, which is amazing. The truth is in the stars.*
- *I graduated from College to nothing. I wanted to work at a gym. That's what I went to college for. Today I work at Goodlife Fitness because someone on my support network knew someone who worked in the main office. She pulled strings. I live outside the city limits and if I take a cab to work, it would cost me too much money. My facilitator contacted my neighbor Pat and I met her also through church. For over a year, Pat takes me and picks me up every day, 3 times a week. Pat is so nice. I want to move into my own place. In November, I'm hosting a meeting at my home and my Facilitator will be there too. I got ideas and want to tell people.*
- *My Facilitator opened up my eyes to a lot more stuff to do with my life. I told her I wanted to teach breakdancing which is not so easy in a small farming town. She told me about a dancer performing nearby. I had an opportunity to perform with him and it was a blast. He encouraged me to follow my dreams. And I did! After that, my Facilitator helped me to think about other ways to share my skill of breakdancing so I did a bunch of summer camps, went to different schools and then she and I met up with a Dance Studio and they hired me. Next District School Board hired me to do several workshops throughout the school year. I get paid a lot to do these workshops. Life has changed from looking forever for the right job in a small town and nothing was happening until I started living my dream! I'm excited about my future now.*

- *His brother tells my son – “I like you better when your facilitator has left.” Our Facilitator is able to get things out of my son without pushing or nagging, helps me to think differently, has this way of getting you to think of things that you may not have thought of for whatever reason.*
- *My son has autism. He got a lot of help from his Facilitator. In high school, he had a lot of difficulty. We had tragedy in our life. He had nowhere to go. He stayed home for two years. It's been a long journey. Our Facilitator helped us through a lot and our whole family is involved. He has a twin who helps him a lot. Every weekend, they do things together. He (brother) works a lot of hours. My son is very, very shy, but with me he doesn't shut up. He is very dependable. He paints sports logos. He is a sports fanatic. His work is very precise...and he's just so proud of his paintings. He's also working at a Community Garden. It's been a long journey. He likes to go to class now. I want him to go to school and be with his friends. I've seen a difference in him. He takes on challenges now. He is coming out of his shell. He is a big helper at school. Takes on helping the most challenged people at school. Shows them his books and his paintings. Always goes to help people.*
- *My daughter was a drawer from an early age. She perfectly reproduced cartoons. Her Facilitator helped us to start to put the puzzle pieces together about what she might do now that she is out of school. She asked us even though she draws all day, what about her beginning an art and drawing class. She started at the parks and recreation adult continuing education. She now is in a Community Living drop in Art Studio. Her first painting was of a Turkey Baster and she did it perfectly. Then she was asked to paint a picture of someone's dog and now people say, I'll pay you for your work. She just had her 3<sup>rd</sup> commission. It wasn't something we thought was going to happen. This became a thread, a way for her to give back to others. This was not just renaming it . . . as one of the things you do, but . . . rather looking at (her Art) as aspects of who she is. Her art as a way that she can define the future for herself.*
- *The Independent Facilitator knows where to look and has great new ideas that I have never thought of – and they worked.*
- *It has been making sure there is achievement in her life.*

- **Greater independence**

- Independence through ongoing support, education and connection, got my new home on my own
- Son now in apartment!

- *I got a place to live in October! I can't wait. I've been in the hospital for the last 10 months. It was ok I guess. I met new people. I like that. I had no place to live. Life has been rough. I lived at home and then had to leave there and live in a motel. I was living in jail. I was told to live in a shelter. There are no shelters that are physically accessible - they kept you in hospital because they didn't have a place to live until now.*
- *Facilitation helps to trigger things in me to help my son. It teaches me it's not about doing it for him, allow him to go through the breaking it down himself and finding what works for him. I'm stepping a little bit back. I'm amazed and proud to part of this community.*

- **Good information is provided**

- Ability to learn – has been very helpful
- It has been a learning experience – how to handle passport money
- Insightful and beneficial
- Housing information was provided

- *Our Facilitator did a lot of research for us, found a mentor and pointed us in the right direction.*

- **Focus on life versus health**

- Staying focused by getting back on track after the low points, brought hope for daughter
- Planning future, takes her future more seriously - has to think for herself
- Expectations are kept high for always doing more - not letting valued contributions and roles be lost

## Goal #2: To gather key messages and insights about the nature of Independent Facilitation from people and families.

People and families shared the following quotes to describe the working relationship with an Independent Facilitator:

- ***The Facilitator was able to gain his trust and build a good relationship with our son. There's nothing more I want than this relationship to continue for the longest time.***
- *Years ago, I got diagnosed with ADHD, a slow learner. It's not that I couldn't do the work. I was just a slow learner. People labeled me disabled. When I was in high school, me and my friend had lots of struggles. We got bullied, sexually harassed. There were rude words. I was always told you can't do regular school work. I was put in the Special Education developmental disability room in my senior year. It was really insulting. My dad told me later that he dropped out and got his GED later. I looked it up. GED is the equivalency of a grade 12. The school told me I would never get grade 12. To this day, my friend and I are still working on our GED. At first, I failed the GED test and I thought maybe the school was right. Since I started with my Facilitator and Action Read program for reading and writing, I had some help, I passed everything except for math. I can still amount to something in life. **My Facilitator let me know that the organization won't give up as long as you want to keep going.** My friend is now going to Action Read and sometimes he does better than me. I've been a guitar player for 10-15 years. Music really clicked with me. Playing music was hard at first to get started. It's a true passion. Never going to give it up! I play my guitar and sing at different venues in my town.*
- *I was very surprised, once high school ends. I thought things would continue but they came to a grinding halt. I was helping her find work and that became my full-time job. I helped her get two work placements when she graduated and she was fired from both of them. I felt like I had been fired. She is so happy go lucky, when she would get fired she would just say to me - just find something else for me. I couldn't do it anymore. The Facilitator helps us with finding volunteering and work. She does some of the leg-work and involves her in all of it. She now has friends. I share a lot of resonance with other moms, I don't want to be the one. **Facilitators help people take steps again and again. Try, try again.***
- *Independent facilitation is life. It's made an impact on my family, work, my marriage. It was my family that needed the help. My daughter went from having her whole life supported by me, she didn't want to be at home anymore. Now she is working, taking accessible transport, she is independent. **Independent facilitation offers flexibility and it's someone that can meet me where I'm at.** I was so fearful of the future before, I wondered if I had to quit my job, and I always asked myself, what happens if this falls apart? Her facilitator is there. I text her, she texts me back. We plan for the future."*

### **Goal #3: To learn from people and families what it has meant to them to have the support of an Independent Facilitator and how it is different from other supports they receive.**

People and families have found that their experiences with Independent Facilitation have been different from other forms of support they have received.

Key messages in quote form that we heard:

- **Focus on Citizenship and Potential**

- Facilitators recognize the potential that is there in each person
- It helps people to believe in themselves, have a sense of purpose and ambition.
- My daughter is now feeling like a person.
- He doesn't just do things he has started to refer to himself as an artist.

- *Our son is a placement artist. We had others help describe him as an artist. In a nutshell...he's nonverbal. He places things in certain places. About 4 years ago he started to do things that we were just amazed about. The first thing, was the building they call the Marilyn Monroe building he could see out the window. The wavy building. He recreated that perfectly with compact disc cases. Our home is like a living home art installation. Our home is like, he declutters the closets so they are empty for art. Nothing is permanent. I started taking pictures. I made collages and sent to families and friends. They didn't know what it is. I called around to art places. When our Facilitator came I told her about the art thing. She did all this research. She's good at that. She helped us to put an ad up in the local art guild. It helped us to find an art mentor. Our Facilitator has helped us with a million other things. He now has his own Etsy website - we are now selling his work. At first it was to spread the word about autism – **now it's not about his disability but about his art.***
- *For two of my kids, Independent Facilitation solidified where they've come and where they will go. There are successes now. My kids have a sense of accomplishment. It offers individuality and someone to advocate against the barriers in the community. We need to advocate now for Independent Facilitation so we can make this available to everyone. My son was not addressed as a person before and he needed the advocacy.*

- **Person-directed, Ongoing Support Relationships**

- Independent Facilitation is a unique approach and should be recognized as such
- Facilitators are creative in ways that would not be possible if they were an agency within the system
- The consistency of having the same person over time is important for individuals and families.
- My Facilitator helped me take “baby-steps” towards my goal of Independence, and most importantly they encouraged me and still do.

- *She (independent facilitator) really got to know a sense of who my son is. He was interested in trees and weather, and now he volunteers at the experimental farm. Our children need that person and someone that cares and is interested. If this ended it would be a loss for my son. She showed him the route. It is personalized and she catered to who he is.*
- *I was new to my town and didn't know anybody really. I moved to be closer to my dad. I shared an apartment with my sister. I had to move out about a year ago and moved to a group home. I wasn't happy because I wanted to live on my own but this was offered so I took it. I really didn't like living in that group home at all. I kept going to Housing Department and asking if they had a place. I just kept going there and letting people know I wanted my own place. I worked very closely with my facilitator and she really helped me every step of the way. The Housing*



Department offered a rent subsidy so that I could find a place in a good area of town. I'm so happy. I'm close to where I used to live with my sister. I know the bus route to get to my job at Boston Pizza. I joined a local biking group. When I started with that group, I started with 5km and now I'm biking 25 and 30 kms with my new biking friends. My Facilitator believed in me and didn't give up either.

- *When I begin to realize that I am a senior citizen and think about the future then it's pretty scary. When my son left high-school, I thought things would be different. I spent time organizing programs, volunteering. It's changed over the years. I'm not going to be able to manage that forever. When I was offered the opportunity about a year ago, I jumped at the opportunity. I have to tell you – at first when we would meet with our Facilitator– I wondered - is it a good thing, or is it a waste of time? This is a process that goes in baby steps. It's not a process where a person comes and then doesn't come. They don't have prepackaged solutions. He can be a genuine actor in his own life. He's not just a passive person; he can be an active person in his own life. He discovered that he is a person who can make stories. He found his voice that way. We are encouraged. We are on the way to get independence and support that he needs when I'm no longer here. It has been a short time -about a year to have this kind of support. He is not just a consumer of services and media. He can be a participant. He's not passive. But he can be an actor in his own life. That makes me cry. I'm really grateful to be a part of the process. Even today – we came today with an artist and a musician - and my son is a person who can make stories. And we are both proud of that. He makes stories. He is interested in travel. He is interested in looking at pictures and figuring out a story about who the person is and what's happening next?*
- *Independent Facilitation is personalized, tailored to the person. It's about what the person wants to accomplish in life, which changes over time. It's not just about services it's about being part of the community.*

- **Supporting people to customize their support, direct their lives, and maintain control**
  - Agencies - will say "here, I will offer you..." but this facilitation – he's not just a passive consumer/recipient of services. No one offers to look at his whole life. This is a qualitative difference.
  - Facilitators help people navigate the larger system that supports individuals and their families.
  - Individualized is about tailoring what happens in one person's life and that is different from the other supports.

- *An Independent facilitator is someone to help me navigate the system. This is HUGE! She helped us find a support person which allows my daughter to take up opportunities. In the group that she belongs to, every day friends, no one has this help. We are the only ones with an independent facilitator. But everyone needs this help.*
- *I learned that I need to bring people with me when interacting with the system. There are professionals in the system who don't treat parents well but when you bring a different professional into the room then we are treated differently. There is a change in tone. Having someone else, others see that they will be held accountable*
- *Thinking differently. Independent Facilitation starts with the person and looks at their whole life – we can get respite, recreation and agencies but we need Facilitators as well for a holistic approach. Independent Facilitators do not offer a service, they make my son an actor in his OWN LIFE! and that is what he wants and what he deserves.*
- *My son is 40 years old and has autism. He lived out of home once in a group home but he got really sick and came back home. They kicked him out. They had a lot of difficulties with his behaviours. They took him to treatment centre for 7 months to deal with that, he came home 10 times worse. They were restraining him all the time. He's not a criminal. He came home with staff ratio of 3 to 1. He went in with a staff ratio of 1 to 1. In the meantime, me and my husband have*

*health problems. We are aging. I have had a huge surgery. It is very scary. It is on my mind - what could happen when I'm not around? So pleased to meet the Facilitator - to help families that are working hard, hoping that government is looking out for us when we as parents are no longer there to support their sons. We are writing a proposal for my son to be supported in his own home. Pray to god. Hope.*

- **Working with people along with their natural supports, such as family members, loved ones, and trusted others**

- The Facilitator was amazing and supported our family as a whole.
- Our Facilitator supports us as a family and makes life easier.

- *My son is an adult. My general frustration is that for example his ODSP cheques come addressed to him care of me but when I reach out for help they only want to speak to my son. I always encourage my son to have an opinion. I don't always agree however because his choices can come with consequences; long term planning is not good. Facilitation works with him in conjunction with us as his parents.*

- **Neighbourhood/community connections are the first option for inclusion**

- It was the facilitator's network that helped connect us to the city.

## **Goal #4: To better understand what people and families need as they take on changes in their lives and how we can serve them better.**

People and families shared the following key messages/quotes about what is needed and what is important to understand in supporting them to move forward:

- **People with disabilities are citizens**

- *People with developmental disabilities are under-rated. The way people are treated in the community, there is not enough knowledge out there.*
- *People are not stupid, we have a voice (person and family). Just because something may sound complicated, you don't have to dumb it down; don't talk over my head, don't talk under my head, talk to my head. People make assumptions that I am more stupid than I am. I can direct my own life; information needs to be presented in a way that I understand.*
- *I want something to satisfy me as a person - something that is me. That recognizes me not as an autistic person who has this disability and drawbacks - but to recognize me as a person who can overcome these drawbacks. I always wanted to achieve something.*

- **People and families see a need for continued and broader access to Independent Facilitation**

- *We are exhausted as parents - it will be much worse if we don't keep getting the support. I would like decision makers to spend a day or a week with our child just to see how much this work this is. If we are sick or not able the Facilitator helps us to let others know. Get resources.*
- *We need the Facilitator to keep going. We are not yet finished she can do so much more with the help of independent facilitation.*
- *Our Facilitator gently walked us through this wonderful process of change, don't see how the ministry could they take that away from families.*
- *The gov't needs to realize that the parents are going through a difficult life - food, shelter - with 3 special kids – it is difficult to pay for day to day out of pocket. We would never be able to pay fee for service for your supports (of independent facilitation). These kinds of organizations need to be funded so they can serve the community better.*
- *Why would the Ministry run a project without showing they were committed and giving ongoing funding? We know this works for families - so now fund it. No more projects.*
- *One of the key messages is that we need and want continuity and consistency. This is unique to facilitation vs. mandated projects. This is a different approach. We have accompaniment as we take on changes. Facilitators provide valuable information.*
- *All families, not just those who participated in the demonstration project, should have access to Independent Facilitation*
- *It would be extremely painful to lose this kind of support. Does the MCSS understand how much work there is still left to do and how many other adults there are who need the same things? It's hard for others to understand where people's lives will be at if this funding stops.*
- *We don't want to re-apply for this support every 3 years - cannot run the system like that, staff without the funds.*

- *We know about the 20/80 MCSS budget ratio - 80% money goes to agency land, 20% goes to people who are supporting individuals in their homes. When that money goes to agency land, it stays within a closed circle. When it goes to independent facilitators and IFOs, there are those holes in the wall - there is a crack in everything. That is how the light gets in. For the greater good. My daughter is that crack in the wall. Supporters who get paid spreads wealth around in community. Agency - they have bricks and mortar to protect.*
- *If we don't continue to have this support going forward, it will be painful. It would be detrimental to us and our family.*
- *Sitting at a desk and talking is not the same. This is going to happen in the person's natural environment their home.*
- *Independent Facilitation gives us the strength to broker supports and services.*
- *This is a way for us to see ourselves in a different way – through others.*
- *Families find it impossible, very difficult to pay for this. In Independent Facilitation, you get more support the more you take on and the bigger you play. The more you do and need support, the more the facilitator will be there. You don't want to worry that's going to cost you more money.*
- *Without Independent Facilitation, we lose the bridge, we lose the transition plan. If you lose the boat, you lose everything. Independent facilitation fills the gaps.*
- *The DSO puts people in touch with formal services and not other options including community. Good Independent Facilitators know the service system as well as the other options that are out there. Better resource.*
- *The government changed so that people can get minimum wage jobs. What happens to people who used to work in sheltered workshops? We want the support of Independent Facilitators to help people get minimum wage jobs, things in the community, and more support.*
- *Facilitation should be offered well before the age of 18 years.*
- *Independent Facilitators are there to push us out of our comfort zones as well as celebrate our successes. Having another voice other than parents or self- advocates helps a lot.*
- *When we started with our facilitator, he didn't like his workers and we had given up on support workers. The Facilitator knew more people and because she knew him she helped us find good people who matched.*
- *Information on Independent facilitation should be part of the package given when someone is starting at DSO.*
- *Facilitation needed more now because of recent trends in government. The way that the government had set things up, value was placed on being in crisis. This pitted families against each other. Now there is a focus on individualization that is growing (ie. passport program provides money that people can decide what they do with it). The problem is that it is easy and socially expected that families will spend that money buying the easily accessible services. Facilitators are needed to help people spend their money in a way that is individual and fits best for the person and family.*

- **People and families want and need more individualized supports**
  - *We need something real. When she was learning basic English, it was over after 6 months, one shot deal - couldn't re-apply. Needed more.*
  - *The Facilitator – is there to help (us) navigate. There is transparency. It is individual support - not one-size-fits-all. Tailoring a person's life. Gov't needs to offer this way of supporting people.*
  - *People and their families need more individualized funding.*
  - *Families realize that they will struggle to embrace the things they want in life, but they just want a little support they can count on.*
  - *ODSP –is for food, housing and you get it for your whole life. The other needs a person has are for life also and they require money. We need this support for life. There was a time when there wasn't ODSP - people thought it was socialism. We are pioneers.*
  - *The first need, for everyone is to get well, to get job. Homeless people are on the road. If I die as a parent, it will be the same for my child- homeless person on the road.*
  - *My daughter has 5 support workers - they get paid - she is an employer – it is the small business owners that help make our economy go around. Workers expand her life options.*
  - *Once upon a time there was no health care. Now you get support. If you are born with a developmental disability, that isn't your fault but it's not a given that you get support.*
  - *"Give me a chance." Not only do I deserve it but I have a lot to do in my life. People need a little break. Shouldn't have to live in a world with labels. Doesn't hurt to get a little support.*
  - *It takes a longer time for grass-roots initiatives to become mainstream. We need supportive infrastructure.*
  - *We (individuals and families) need to educate our politicians.*
  - *We need to tell MCSS - Help people to plan and get on with their daily lives*
  - *There was a parent Movement in the 1970s - marches in Queen's Park. Radical. We had a Fax night – we sent 1000 faxes to the gov't. Marches. Protesting. Maybe we need to think about that. They are organizing in the north- Parents of Adults with Disabilities (PADD) in Windsor and North Bay.*
- **When people and families are strengthened, they are empowered to support one another**
  - *Helpful to see what happens when people come together and start moving in the same direction. We need to come together and have this connection to imagine the future better.*
  - *Families want the support of family groups so they can strengthen one another.*
  - *Parents would like to hear from other parents on what they have gained from independent facilitations which can help them with future planning of their family member.*
  - *IFOs need money to offer a retreat - to learn together because this kind of learning together is helpful. Family's value connecting in these type of networking events so they can be inspired by each other. We need IFOs to bring us together.*

**Goal #5: For people and families to identify what is needed - assistance with recruitment, hiring/contracting with paid people (service provision), independent facilitation, advocacy, direct individualized funding that is more than \$35,000.00.**

People and families identified the supports that are needed in addition to independent facilitation for people and their families to have a good life. Key messages (quotes) that we heard are included below, organized by theme:

- **A community that is welcoming**  
This means that people are welcomed to contribute in their community. They have real jobs and are paid not always volunteering.
- **Where to find good information**  
There is so much information and it is difficult to find it and manage it. Information is always changing; the Ministry is always making changes. Some suggested that having a one stop place where they could find any information they need would be helpful.
- **Supports to navigate the school experience**  
Some school experiences have not been positive. People and families experience challenges navigating the school system. Some parents suggested they wanted a champion that could accompany them to speak with school officials. Parents want more opportunities for their children to be included in regular classes and school experiences. Some people need more supports while in school and there is currently not enough support for people to be included.
- **More opportunities for people and families to connect**  
People and families want opportunities to get together to provide support to each other and to learn from each other. Parent support groups were suggested. Informal gatherings like more dinners were also suggested.  
People want to be able to gather with like-minded people who share their interests. They need personal connections and friends. Support networks are important.
- **Address barriers in rural communities**  
People and families that live in the more rural areas of Essex County identified a lack of resources. They also said transportation is a major barrier for people to access opportunities in their community.
- **More flexible uses for Passport funding**  
“Need money to have freedom – to have a life.” It would be of benefit if people could use Passport funding for assistive devices especially for communication, cell phones which are a primary resource to increase independence.
- **More funding to support living independently**  
In order to live independently people need to have affordable places to live. They also need flexibility in their funding so they don’t have to worry and can be involved in social activities. They do not want to have to choose between paying rent and being social.
- **Microboards**  
Microboards are rooted in the values of citizenship and supported decision-making. They are also a legal non-profit corporation that works on behalf of the person. They are a formal support network.