

## **“Ask Me First” Advocacy for Voice and Choice**

February 2004

***A Key Message from the Individualized Funding WorkFest***

### **From Harm to Hope: Moving to Self-Determination**

Citizens who have been labelled have experienced much harm over the years. Large institutions that dominated service systems in the 19<sup>th</sup> and 20<sup>th</sup> Centuries were a tragedy in separating people from their families and their communities. Many community service systems continue to teach compliance and keep people away from community life. Many individuals who have been labelled call themselves self-advocates, to indicate the importance of each person having their own voice. Yet, self-advocates say over and over that their voices are often not heard. Self-determination, which includes genuine voice and choice, is difficult to realize when other people make decisions for us. It is also hard when many of us are surrounded by services, instead of having the supports we need being designed for our personal dreams and needs. “Ask Me First” is a powerful theme that is central to Individualized Funding. With this approach to self-determination, the person is listened to and totally involved in the process of developing their personal disability supports plan. This plan then forms the basis of an application for Individualized Funding. “Ask Me First” also applies once the plan is being implemented. The person has a major role to play in terms of deciding when, where, and how they want their individualized supports provided. Self-advocates recognize that this process is difficult to carry out alone. Inviting other family members and friends to be part of one’s planning network can be very helpful. This can also be a good way to expand relationships, which help us to feel less isolated.

### **The Vision When “Ask Me First” is Central to Disability Supports**

*Citizenship is central as a goal and as a lens for decision-making*

- There is a collective commitment to honour the voices of self-advocates
- Families and self-advocates have more self-confidence
- The fundamental messages comes from people who require support.

*Nurturing the groundswell*

- There is a co-ordinated network of people with a united voice, clear & focused message
- The principle of self-determination and “Ask Me First” is accepted and widely utilized
- People First of Ontario has its own resources and has new, young leadership.

### ***The Value of Self-Determination***

Projects that are based on self-determination principles give voice and choice to the person. Self-determination Projects in 19 US States have four key principles:

- freedom to plan your own life
- authority to control funds for supports
- support through formal and informal resources
- responsibility to participate in valued roles in the community.

Self-determination is best experienced in community, where participation with people and welcoming places makes one feel they are being heard for who they are, not their label.

*Sharing the good news*

- Self-advocates and families tell their stories about individualized planning, support, and funding
- Definitions and the elements of individualized planning and funding are shared with families, self-advocates, and service providers
- “Ask Me First” is a predominant theme in IF campaigns.

## **Barriers to a self-determination and “Ask Me First” vision**

*Very little understanding of what “citizenship” means for vulnerable citizens*

- People with disabilities are not valued or considered citizens
- Few people know how to/or appreciate the value of listening to vulnerable people
- Some disability supports are seen as privileges, rather than rights.

*Government policy-making does not include vulnerable citizens and their families*

- Voices that government listen to are not OUR voices
- Ministry policy-making fails to engage families and self-advocates, both centrally at Queen’s Park and in the MCSS regions
- People are afraid to ‘stick their necks out’ for fear they will lose what they have.

*Lack of resources for self-advocacy (People First) and for family networks*

- Self-advocates (and many families) do not have resources to tell stories
- Government money all goes to services, not to family or self-advocate initiatives
- There is very little independent planning (a good way to enhance self-determination).

## **The Hope of Stories: Self-Determination and Person-Directed Planning**

When Kathy was about to leave high school, she and her family became involved in a Foundations Project, designed for 18 to 29 year old youth. Kathy did not have any career goals and her parents were worried that she would just “sit at home,” unless they could make plans that got her engaged in the community. A facilitator spend a lot of time with Kathy and her parents, and separate time with Kathy to find out some of her dreams, and things she really liked. Although it was new to Kathy, she really took to the idea that what she said mattered. Kathy and her family agreed to hold a small gathering of friends who could help them plan what Kathy would do when she finished high school. The facilitator had worked with Kathy to say what she wanted and in that first meeting; Kathy presented a big picture of some things that were important to her. The facilitator asked others to help identify what people and what places might support the dreams Kathy had. Since one of Kathy’s dreams was to work with clothes, lots of people and places in the fashion industry were identified. Over the next two weeks, Kathy and the facilitator met to develop a detailed support plan that outlined what places Kathy wanted to visit and who she wanted to help her. Shortly after that, Kathy had an the opportunity to interview three people, one of whom was hired to help her find a retail place where Kathy could work, and other places in the community where she could do volunteer work. When Kathy was recently asked what she liked about this process. She said she like the facilitator, she liked that she could say what she wanted and people listened. Most of all, she said, she liked hiring who would work for her!

## **Strategies for Enhancing Self-Determination and “Ask Me First”**

*These strategies are designed to enhance self-determination, and to ensure that people with disabilities are central in individual planning as well as in policy-making processes. Specific strategies are:*

1. To develop leadership that understands self-determination and “Ask Me First” by:
  - Finding and nurturing authentic new leaders, especially self-advocates
  - Promoting the voice and choice of people with disabilities in all the elements of Individualized Funding
  - Creating materials that stress “Ask Me First” in independent planning, and in government decision-making and policy development.
  
2. To access new resources for promoting self-determination and “Ask Me First” by:
  - Working in partnership with provincial organizations to raise money or “in-kind” resources for IF and “Ask Me First”
  - Assisting People First of Ontario to access resources for their work.
  - Educating government about the value of independent self-advocacy organizations and independent family organizations related to self-determination and individualized supports.

### **Outcomes by 2006**

- Citizenship will be well understood by all stakeholders.
- Self-determination and “Ask Me First” will be accepted as a major value related to Individualized Funding.
- Self-advocacy and People First will have a vibrant presence in the IF movement.
- Stories of self-advocates and families will be prevalent in the IF movement.
- Self-advocacy and family groups will be funded each year.

### **Outcomes by 2006**

- A definition of Individualized Funding that is based on self-determination and citizenship will be well understood across all stakeholders
- Newsletters and other communications vehicles will routinely have articles on individualized approaches
- The elements that enhance Individualized Funding will be widely understood and experienced by many more families.
- Individualized Funding and independent planning will be in place in all areas of the province, with carefully developed infrastructures that meet local needs.
- Government and families will have worked collaboratively together to develop the approach to IF and the elements
- More service providers will be encouraging and supportive of families that want to be engaged with individualized planning, support, and funding.