

Common Vision

for

Real Transformation

June 2005

Part 1 of 2 Parts

We are Four Provincial Organizations that Represent Families and Individuals with Disabilities

Family Alliance Ontario

Supporting the well being of persons with disabilities and their families, and promoting the inclusion of persons with disabilities into all aspects of community life.

Individualized Funding Coalition for Ontario

Supporting a coalition of individuals, families, and community agencies dedicated to self-determination, including having access to and control over funds for disability supports.

People First of Ontario

Supporting people who have been labelled to speak for themselves, to help each other, and to help make sure that they are heard.

Special Services at Home Provincial Coalition

Supporting a coalition of individuals, families, organizations and agencies dedicated to ensuring that families in Ontario receive the meaningful support they require through SSAH

Our Purpose with a Shared Vision

The Ontario Ministry of Community and Social Services (MCSS) and its community partners are currently engaged in a “transformation process.” This two-part newsletter reflects agreements across our four organizations in regard to transformation of developmental services in Ontario. It

also broadens the discussion to every aspect of living.

Transformation in the way supports are provided is needed throughout Ontario for citizens with disabilities. Over the years, all of our organizations have been building a new story with families and individuals with disabilities. The new story has a common vision:

A good life for people with disabilities as citizens within our communities.

Learning from our History

Opportunities & Experiences to Build On

Ontario has a history rich in innovation, implementation, and learning. This includes:

- ◆ **More than twenty years of experience with the Special Services at Home program (SSAH).** We have a generation of families that have experienced individualized supports and control over those supports. Families want this to continue as their children move from the family home.
- ◆ **The Ontario Ministry of Health & Long Term Care has more than a decade of experience with the Direct Funding Project.** This project provides individualized funding to adults with physical disabilities who can direct their own support. Many individuals and families who require support and accommodation to direct their supports now want this same opportunity.
- ◆ **Eleven pilot projects across the province in the 1990's provided MCSS with information and insights about individualized planning, support, and funding.** Some of these initiatives continue to provide innovative leadership from which we can learn. We want to see these positive learnings translate into positive policy change for all.

- ◆ **Many families have experienced a shift in their thinking, and are ready for transformation.**

Historically, families have been taught to stay on “waiting lists” for support and services. More and more, families are creating change within their communities, building networks, and seeking support for participation and contribution. Families are ready for genuine change that supports the dreams and strengths of their sons and daughters.

- ◆ **People with disabilities have been pioneers in asking for new approaches and are contributing to how transformation can happen.** Whether it has been

People First groups running “Keeping Your Dreams Alive” workshops, sharing their stories or people speaking up in their local communities, people are demanding rights as well as genuine choice and opportunities.

- ◆ **Ontario signed the Federal-Provincial agreement, In Unison,** which calls on the provinces to provide individualized disability supports, controlled by the person and their family.

The New Story is about valuing the voice and choice of individuals and families, and creating conditions and structures that honour those choices.

Learning from our History

Barriers and Drawbacks

Our history has also provided us with opportunities to learn about what we do not want in our future. **We do not want:**

- ◆ **A system that has resulted in passive and dependent families over the years.**
The wait for services has been so long that many families feel that they will never get the services they need.
- ◆ **People to be labelled.** The time has come to stop labelling and to start supporting people. We know that labels limit people and that the stigma that results often isolates people from community.
- ◆ **Individuals and their families/support networks to be disempowered.** Too many individuals and families still have inadequate information, limited choices, and few relationships.
- ◆ **Government ministries that are not all investing in inclusion.** People benefit from support and funding from more than one ministry. Community supports would be more accessible and supportive if there was a common vision and seamless funding.
- ◆ **To continue to fund programs instead of people.** Individualized funding and portable funds empower people and helps to transform services.

What We Mean by Transformation

Transformation Means:

- ◆ **Change** that reflects current research and best practice.
- ◆ **Change** that involves the full participation of individuals and families.
- ◆ **Change** that is based on the values of citizenship and inclusion.
- ◆ **Creating a new story and a new system** where decision-making rests with individuals, families and support networks.
- ◆ **Moving the current system away from a paternalistic approach,** where power is invested mostly in agencies, to a system that recognizes the need for partnerships and new approaches designed to empower individuals and families.
- ◆ **An openness and willingness to learn** from innovative, person-directed approaches and from what individuals and families/support networks genuinely want.
- ◆ **Working together** based on respect and integrity. As Margaret Wheatley says:
If we work together more intelligently, we will need to choose processes that evoke our curiosity, humility, generosity and wisdom.

Values: The Foundation of Transformation

We share the following foundational values as part of a transformed system:

- ◆ *Citizenship*
- ◆ *Self-determination*
- ◆ *Inclusion and community engagement*
- ◆ *Individual and family empowerment*

Citizenship

Citizenship embraces both self-determination and community

Citizenship is a value we take for granted, but people with disabilities are often denied the rights and responsibilities of being a full citizen. Citizenship involves access to rights, valued status, and full participation (I have the same rights as others...I am important...I can participate everywhere in my community). Citizenship also involves choosing from a range of community opportunities that enable one to learn, explore, and participate. Citizenship is seen as one of the bridges between community and hospitality. Mark Kingwell describes citizenship as **“a way of meeting one’s deepest needs, the need to belong; it gives voice and structure to the yearning to be part of something larger than ourselves.”**

Enhancing citizenship with hospitality and participation is one of the hallmarks of individualized supports that work for people.

Self-determination

Everybody has the right to self-determination – everyone is included.

Self-determination is a process of people determining their own needs and interests (I decide . . . I choose . . . Others get behind me . . . I am heard when I am speaking up...). It means individuals choose and decide (with support as needed) about their life choices and the type and quality of support they want. We have learned a great deal about self-determination in recent years. We know that all human beings seek their own path and that when we listen deeply, we can enable individuals with the most significant disabilities to express their desires. Strong relationships help facilitate self-determination, which is why support networks are so important in any new approaches. As Raymond Kilroy said:

“We are moving from programming me and other people with disabilities toward empowering us and our families to acquire the support we want. We are moving away from focusing on my deficits to focusing on my competence.”

Social Inclusion and Community Engagement

Inclusion is both a process and outcome that enables every citizen to participate and belong in all settings in their communities.

Social inclusion is a term that many groups are now using. It means people working together to create welcoming communities that include everyone. A community learns as people are present. It cannot learn if people are absent. For people with disabilities, inclusion means realizing your dreams and desire for participation. Inclusion is embedded in relationship building. Catherine Frazee, former chief commissioner of the Ontario Human Rights Commission, emphasizes that relationships matter as much as rights. She points out that citizenship and inclusion mean belonging.

“Belonging in schools and universities, in places of work and places of worship, in politics, art and commerce; belonging in family, community, and nation.”

Community means neighbourhoods, personal networks, and associations or groups of common interest. A commitment to inclusion ensures that supports are provided so people can participate and be part of community. Furthermore, the community engagement of citizens with disabilities creates opportunities to educate neighbourhoods and to invest in relationship building. With effective individualized planning, community development happens in natural ways when a person is included.

Individual and Family Empowerment

Empowerment is a process whereby people gradually gain more control and participation in their lives.

The value of empowerment is that it enables us to understand what helps families and what doesn't. Using empowerment as a lens, we learn that facilitating power and participation for individuals and families is enhanced when advocacy, independent planning/facilitation, allocation of funding, and direct services operate as separate functions in the system. In this way, individuals have more control over their lives with the help of family, support networks, and a facilitator. Separating these functions also enables people to build their own capacities and networks, and have more power within the system.

Empowerment is also enhanced when people have the opportunity to access valued resources that satisfy basic human needs. This value builds on the assumption that a transformed system must shift power to vulnerable citizens by paying attention to creating positive circumstances for participation and the expression of self-determination.

The void in our society has been produced by the absence of values.

John Ralston Saul

Values are the bedrock of political and social life; they are our conception of the good, of what is desirable.

Janice Gross Stein

Shared Principles in a Transformed System

Principles can be thought of as guidelines for practice that reflect our values. We share the following principles as part of a transformed system.

- ◆ **Independent planning and facilitation is available** for all individuals and families, and is separate from direct service provision.
- ◆ **Funds for disability supports are portable**, and can be moved at the discretion of the person and their family and their network.
- ◆ **Individualized funding is available** for all disability supports and can be applied for by individuals, families/support networks.
- ◆ **All funding is attached to a person**, regardless of the type of support they choose.
- ◆ **Funding for housing is separate from or de-linked from support programs**

- ◆ **Allocation mechanisms ensure that people have access, fairness and equity.**
- ◆ **Accountability mechanisms are simple and understandable**, and they create feedback about how plans and funding are fostering citizenship and participation.
- ◆ **Innovation is encouraged, supported and funded** for service providers and others. It is a key mechanism for evolution and progress.
- ◆ **Strong autonomous family networks and People First groups are supported**, and they have an important advocacy role in the transformed system.

We want to see these practical principles and directions used together to enable individuals and families to experience real transformation and full citizenship.

For the new story and individualized funding to work effectively, “Infrastructure supports should include the provision of information, independent facilitation and person-directed planning support, network building support, and ongoing implementation support, including payroll and administrative support.”

Report of the Ontario Round Table on Individualized Funding

Principles and Directions for a Transformed System

Principle and Direction # 1

Independent planning and facilitation is available for individuals and families, and is separate from direct service provision.

What We Want - Directions

- ◆ Independent facilitation and planning support that is valued and funded by the government.
- ◆ The freedom to choose our independent facilitator.
- ◆ Independent facilitation and planning support that includes: deep listening, resourcefulness, and a plan that works for the person.
- ◆ Independent facilitators who are trained in value based facilitation and planning, are accountable to the person and his/her family and their network, can balance the voice of the person with family input, and recognizes and works with support circles/networks.

Why We Want It - Rationale

- ◆ Many people and families need facilitation support to build their capacity and to develop meaningful life plans.
- ◆ A third party who is not connected to services can ensure that planning will be broad, empowering, and community focused.

- ◆ Independent planning and facilitation creates a balance of power and knowledge, and ensures that individuals are heard.
- ◆ It helps people to develop networks, increase their community connections, and expand their relationships.
- ◆ SSAH has very limited infrastructure and that has caused difficulties.
- ◆ Independent planning and facilitation over time identifies strengths and issues in the community that can be addressed through community development.

How to Make it Happen - Implementation

- ◆ Develop guiding principles for independent planning and facilitation.
- ◆ Insure that good quality valued based planning and facilitation is available in all regions of Ontario.
- ◆ Locate facilitators in non-direct service locations, not in Access Centres or with advocacy groups.
- ◆ Base principles and directions on current research and practice in Ontario and elsewhere.
- ◆ Collaborate with people who have experience with values and principles of independent planning and facilitation, and support them to train facilitators.

Principles and Directions for a Transformed System

Principle and Direction # 2

Funds for disability supports are portable, and can be moved at the discretion of the person and their family/network.

What We Want - Directions

- ◆ To be able to move disability support resources from agency to agency, or from an agency to self-directed supports, or from one area of the province to another, or from home to community.
- ◆ To use resources in a way that best meet the needs of the individual, their family and support network, with the assistance of a facilitator if necessary.

Why We Want It – Rationale

- ◆ It strongly reflects the values of self-determination and citizenship; people can choose where they live and who they want to support them.
- ◆ People are hurt and wounded when they live in environments that they do not value. Research shows that health and quality of life improve when people have more control and participation.

- ◆ It creates equity of opportunity and increased choice for all.
- ◆ It is respectful.
- ◆ It is administratively efficient and, because people can take their resources elsewhere, it provides some pressure on everyone to provide high quality supports.

How to Make it Happen - Implementation

- ◆ Develop guiding principles for portability, and ensure that all service agreements between the agency and government include a portability clause
- ◆ Base principles and practice on current research and practice in Ontario and elsewhere.
- ◆ When a person wants to move from a congregate setting; provide support to all parties during transition, allow 'time' for notice, engage in a process of negotiation
- ◆ Provide bridging dollars to agencies.
- ◆ Make SSAH portable immediately as the first phase of transformation

For further information, see our web-sites:

Family Alliance Ontario: <http://family-alliance.com>

Individualized Funding Coalition for Ontario: www.individualizedfunding.ca

People First of Ontario: www.peoplefirstontario.com

Special Services at Home Provincial Coalition: www.ssahcoalition.ca

Also see Common Vision, Part Two.

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