

# Transformation of Developmental Services:

Expanding the Possibilities for Citizenship

A Signature Paper Developed by the

Individualized Funding Coalition for Ontario

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This *Signature Paper* is a synthesis of many of the writings produced by the Individualized Funding Coalition for Ontario on the subject of Individualized Funding and Independent Planning and Facilitation.

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## **Introduction**

Across Canada, people with disabilities, their families, friends and others -- those in their personal networks -- as well as People First, family groups, forward-thinking agencies and even governments are actively promoting citizenship and the transformation of systems and services for people with disabilities.

The cry for change at this time in history is for people with disabilities to be able to live their lives as full citizens with the supports they need. Experiencing a good life means not being dependant on systems built on decades old principles. It means changing things for the better.

We know so much more in the year 2007 than we did fifty years ago at the onset of a service system that was developed to support people with disabilities. We know that it is possible for people with disabilities to direct their own lives, often with the assistance of family, friends and others. We know that individualized funding and supports like independent planning and facilitation and network development -- building and maintaining relationships with family, friends and others -- moves us closer to empowerment for all citizens. This new knowledge and actions that are needed form the essence of this paper.

### **Purpose**

The purpose of this paper is to outline values and principles, policy framework, and directions needed to ensure the building and the implementation of a transformed developmental service system in Ontario.

Special emphasis will be placed on two key elements of transformation: **individualized funding** and **independent planning and facilitation**. It is the planning and facilitation process that is most important for bringing family, friends and others together to support the person who has a disability with their dreams of a full life – this is commonly termed ‘building of support networks.’ It is our intention to create a vision of what is possible and in turn assist others in their understanding of what is needed in order to build a successful system of individualized funding in Ontario.

We believe the development of this changed system would:

- Have the potential to reduce loneliness and separation from community for people with disabilities
- Result in true participation and inclusion for citizens with disabilities who would choose this path - making life more accessible and
- Not cost the government any more money than it is already spending.

## **Who We Are**

The Individualized Funding Coalition for Ontario's membership includes: people with disabilities, families, friends, advocates, researchers, facilitators, community members, local Family Networks, People First groups, provincial organizations - federations and coalitions, and local service providers. The 'Coalition' represents sectors of our society who are interested in creating disability supports that are flexible and responsive to the person who has a disability, along with their personal network, which would include family, friends and others - those he or she trusts the most.

## **What We Believe – Our Accord**

The Individualized Funding Coalition for Ontario supports the self-determination of persons with disabilities. We believe that all people should have control over decisions concerning where they live, with whom they live, with whom they associate, and how they spend their lives.

In order to achieve this, we recognize that Ontario must develop a system of funding whereby the person requiring assistance, supported as appropriate by family and or significant others, has control over the funds allocated for his/her support.

## **Directions**

This paper reflects research and best practices related to individualized funding and supports from around the world, including individualized funding initiatives in Western Australia, Great Britain, British Columbia, Ontario, and some areas of the United States. We now know and understand that 'best practices' are closely linked with

good policy direction, clear values and principles, solid infrastructure supports, and intentional community capacity building.

**‘Solid infrastructure supports’** mean that there would be places/organizations to support the functions that are needed in an individualized funding model. It is like looking at new technology and changing accordingly. We would not cross the river on a boat once a bridge is built to take our car. We would not use a Commodore in 2007 when computer technology has advanced so much further.

To advance the ‘new technology of individualized funding’ certain support functions and infrastructures are needed. Just like a bridge gets a car from point A to point B, so does the right infrastructure help a person figure out how to get from point A to point B in their life when utilizing individualized funding. This includes things like: independent planning and facilitation, individualized human resource support, and financial accounting, all of which will be discussed further in this paper.

**Intentional community capacity building** means that community development work would be done in a carefully planned way. Building capacity through community development will vary with each community, and reflect the strengths, gifts and current evolution in that community. The grassroots – people with disabilities and families - would be actively involved along with government and service leaders in the community.

Intentional community capacity building tends to be new to governments, but research is showing that the best way to resolve complex issues is to be sure that all the main players are at the table for planning and implementation. With such an approach, there would be no room for top-down or cookie cutter bureaucratic approaches.

Based on our research, knowledge and experience, we have developed a “Made in Ontario” approach to individualized funding – one that is viable, possible and very do-able! It is outlined in this paper.

The Individualized Funding Coalition for Ontario has developed recommendations to guide the Ministry of Community and Social Services (MCSS), other Ministries, communities, people with disabilities, families and friends, facilitators, and service providers. These recommendations outline a solid policy framework and viable implementation strategies. They are detailed in this paper, utilizing the following framework:

- An adherence to a citizenship approach
- Investment in infrastructure
- Initiating a community development approach.

### **The Governments' Proposed New Directions**

Currently, there are programs and policies in Ontario that provide individualized funding to individuals with disabilities. However, these programs and policies are limited. The MCSS document *Opportunities and Action: Transforming Supports in Ontario for People Who Have a Developmental Disability (2006)* has provided a framework on which this government could build a comprehensive approach to individualized funding in Ontario. This proposed new direction requires a commitment from government to an implementation plan that includes investing in infrastructures designed to support individualized funding and enable people with disabilities and their families to create a good life in community.

The Ministry of Community and Social Services has an opportunity to learn from the past, prepare for the future, and develop a transformed system that will change the way we think and act about support and services designed for people with disabilities. *Opportunities and Action* has begun to lay the foundation. History has provided the seeds.

*Strong vision and strategic planning and implementation are now needed to make the leap into real transformation that can be potentially available to all who want it.*

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*Generally, research to date on the effectiveness of new paradigm approaches has been quite positive. Studies show that costs for individualized funding are usually comparable — costs are similar to conventional supports, but quality of life outcomes are usually much better with individualized funding. Recent research suggests that the emphasis on self-determination in new paradigm projects is one reason for positive outcomes. 1*

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## **Building on Our History in Ontario**

Ontario has a history rich in innovation, implementation, and learning. We have more than twenty years of experience with the *Special Services at Home* program – an individualized funding program proven successful over and over again, despite its limitations. We have more than a decade with the very successful Ministry of Health and Long Term Care *Direct Funding Project*. There have been eleven different MCSS individualized funding pilot projects or programs in the last fifteen years. There is much experience to draw from.

People with disabilities and their families have been pioneers in creating and asking for new approaches, more flexibility, and a system which provides them with more choice and control over their own lives. Many are creating change within their communities, bringing others together and seeking support for their lives in a way that honours their dreams and strengths. Many people are trying hard to live the life they want and desire but now need effective government policy, legislative authority, and an effective implementation strategy. They need to be able to receive the funding and support they require in a way that makes sense to them. They need to know that achieving their own ‘good life’ in their own community is possible.

In the past, there has been much focus by government and service agencies on how to improve existing services for people with disabilities. Although noble and honourable in its intent, this approach by itself has not resulted in new paradigm change. It has failed to promote the idea of people living as full citizens, directing their own lives with the help of family and networks, and participating and contributing to their communities. This one-layered approach to change is very limited and only focuses on improved services for people rather than emphasizing new ways of supporting people to create a life in community. The focus on service outcomes alone rather than quality of life fails to address citizenship goals as defined by people themselves.

## **Developmental Services: Moving Toward a *New Story* Based on Citizenship**

There are currently people and places in Ontario that reflect creativity and innovation. It is these pockets of innovation that are the building blocks of the future for people with disabilities, their families, friends and others. Some are calling this the *New Story* for people with disabilities. The term *New Story* was coined by John Lord and refers to the paradigm shift away from the welfare model and the move toward a citizenship-based structure that ensures that people with disabilities, along with their families, friends and others create a life that makes sense for them in community with the supports and services of their choosing. (See Appendix A)

*"There is nothing more powerful than an idea whose time has come" "*  
*Victor Hugo*

The Individualized Funding Coalition and its members are committed to a transformed system that is based in citizenship and choice for people with disabilities, their families, friends and others in their life. The *New Story* builds on our knowledge, capacity, and strengths in communities. In order to support this *New Story*, the transformation of developmental services and the implementation of individualized funding must:

- Be grounded in vision and values
- Be guided by *New Story* assumptions
- Be built upon practical principles, directions and practices
- Include elements of a citizen-based structure
- Create a solid foundation for the transformation of developmental services
- Have a clear implementation strategy.

### **Vision and Values**

*Vision.* A vision grounds a system in possibilities and new values. A vision needs to be based on a set of values that reflects a *New Story* or new paradigm of disability and community. Individualized Funding supports the vision of citizenship, one that

offers choice and control to citizens with disabilities, with the expectations that people will take control and choose their direction with the right supports in place.

*Values.* Fundamental to the vision of citizenship are two values of utmost importance:

*Self-determination* – the belief that *all* citizens desire to have choice and control in their lives, especially over the disability supports they require.

*Community* – the belief that *all* human beings desire to belong and participate with others in families, neighbourhoods, networks, and groups.

Based on these values, the contribution and participation of individuals, their families, friends and others become key to any new approach – participation in deciding how to build a good life, participation in deciding what kinds of disability supports make sense, and participation and contribution as citizens in the wider community.

## **Assumptions to Guide Us**

There are several assumptions that guide the *New Story* and the transformation of developmental services. In order for individualized funding to be successful change is required.

- Change is needed, because the current system is based on predetermined programs rather than choices, which means that self-determination and citizenship cannot be exercised
- Change is needed, because we now know that every person, regardless of disability, can participate and contribute
- Change is needed because separating functions is necessary for real choice to occur. The 1950's model of support put every function under one roof - which at the time was what 'we' knew to do. We have learned that there are inherent limitations to having planning and facilitation, direct services, advocacy, and allocation mechanisms together within the same agency structure. It actually creates a conflict of interest
- Change is needed, because the current system does not lend itself to innovation. Large service organizations with so many functions tend to be so busy 'managing' that innovation is usually very limited

- Change is needed so that the right tools can be made available to people and families and this will start to move them away from dependency to empowerment
- Change is needed because we know that the capacity of everyday communities to include people and provide opportunities for them to participate and contribute can be developed when done with intentionality.

## **Practical Principles and Directions**

The *New Story* is based on clear principles. There are five principles that provide fundamental directions for the transformation and lead us closer to empowerment. All of these principles must be in place in order for people with disabilities and their families to truly realize the benefits of individualized funding within a citizenship structure.

1. The power of **decision-making** rests primarily with people with disabilities, families, friends and others – those they trust (support networks).
2. **Community** and all the resources we find in community is the vehicle for change and the first resort for building a good life.
3. **Planning and facilitation is independent** from direct service provision and includes effective listening, information provision, bringing people together in support networks, facilitation, planning, mediation and negotiation – whatever the person needs. Planning and facilitation would be funded by government and available in an independent location.
4. Funds for disability supports are **individualized and portable**. Individualized funding comes from government - either from existing base budgets that are unbundled or new funds.
5. Making application to access the service system and the process of allocating funding are **separate** from service provider agencies and their influence.

## **Elements of a Citizenship-Based Structure**

The *New Story* has a very different look and feel from the current system. It is important to imagine what that new system might look like. Individualized funding within

a citizenship structure always remains coherent with the vision, values, and principles of citizenship and self-determination.

The following elements are present in a citizenship-based structure:

1. **Portability of funds** – People with disabilities and their support networks would be able to move disability supports and funding that are designed for them to any location or agency within the region and the province. A respectful and reasonable time frame would be required and be in place so that dollars could be moved from an agency. When dollars are already in an individualized budget, moving those dollars would be easier but would still require a process that is respectful. With true Portability, when a person moves to a new region, the support dollars would also move.
2. **Independent planning and facilitation** – People and those they trust would have access to a facilitator on an ongoing basis who: listens deeply, provides information, assists with planning, helps with network development, does negotiation as needed, mediates and brokers for better supports, explores community and does community development. All this is based on the strengths, capacities, and self-determination of the person, their families and networks.
3. **Individualized Funding** – People and others they trust would have access to the public funds they need for their disability supports. Funding would be based on a support plan that is developed by the person, along with their family and friends, with the support of an independent facilitator. *Our data also showed that people were experiencing extensive participation in community life as a result of individualized funding. 2*
4. **Individualized allocation process** - The allocation process is based on criteria or principles for funding and utilizes regional and/or local approaches for priority setting and the allocation of funds through processes that are equitable, respectful, private, and without agency influence.

5. **Accountability** – Accountability is the process of insuring that those involved with the person with a disability are in fact doing what they say they are doing, personally, financially, and collectively. Accountability is a two-way process. People and families are accountable to government for the expenditure of public funds, while independent facilitators and direct service providers are accountable to the person by ensuring that the person’s plan and goals are being met.
6. **Quality assurance and monitoring** – Quality assurance begins with the assumption that everything evolves as directed by the person and their network. Building relationships, responding to person-directed plans, and engaging and training workers are all done with the person’s goals in mind. How well things work out must be measured against those goals. In addition, basic standards and expectations around labour laws and the employment standards act would set the bar for all workers - self-employed or self-contracted.
7. **Innovation** – The system would have the capacity to support innovation, including funding and/or support for autonomous family and consumer groups, incentives for service innovation, bridge financing for agencies when people want to change their lives and move their dollars, and support for community building in general.
8. **Evaluation** – Evaluation is an important shared responsibility. A commitment to evaluation, learning and the sharing of this responsibility and information would be an integral part of the success of individualized funding in Ontario.

### **Separate Functions**

Service systems and communities by their very nature have different ways of responding to people with disabilities, and their families/support networks. Systems tend to be very structured, bound by rules, predictable, slow to respond to change, lack innovation, and are reliant on what they already know. The current welfare model of supporting people often makes the assumption that a service provider can and should

meet all the support requirements of a person. On the other hand, communities tend to be organic, messy, innovative, and dependent on networks, relationships, and the collaboration of its citizens. In a community, there may be many different places in which people can have their needs met as well as have an opportunity to contribute.

Individualized funding in itself is not transformative. It requires infrastructure to support all that is possible when creating a good life in community. The *New Story* emphasizes the importance of people with disabilities, their families and networks having **access to an ongoing planning and facilitation process** – lifelong, as needed. To be successful, this planning and facilitation support works best when people have a strong relationship with the facilitator, have developed trust over time, and the facilitation process is authentic. Steeped in the principles and values of citizenship, independent facilitators do their work in the community, with the person and their network. This is the place where they can depend and rely on the innovation, creativity, and collaboration with citizens. However, direct service agencies provide an important and necessary role as well. With their vast experience, they will continue to provide many of the direct services and supports that people need in their lives. The healthy tension created with having separate functions leads to creativity and change!

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*At the heart of all the planning approaches is the belief that every single individual has their own life to lead – a life that is right for them. As a result, everyone's plan will be different. 3*

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*Planning and Facilitation, Allocation and Access to funds, Advocacy, and Direct Service Provision – Separate functions within a service system are a necessary support to individualized funding and system transformation. (See Appendix B)*

## **Key Elements of Direct Individualized Funding**

Direct individualized funding is an individualized approach that provides disability support funds directly from government to a person and their family/network. Individualized funding provides genuine choice for the person to direct how their support funding will be used. Once a person has a support plan approved, funding flows directly to the person with a disability and their family, or a designate the person may choose (such as having the funds paid directly to a transfer payment agency). In a direct individualized funding approach there is no need for disability support dollars to be allocated from multiple funding sources and programs. Because the person, often with the assistance of others, has choice and control over the funds, he or she is able to use them in the way that best supports their life in community. Direct individualized funding is flexible and portable. It allows for the changing needs of a person and their circumstances.

Research shows that people who receive disability supports through individualized funding are highly accountable for the money they spend. People are accountable to the Ministry of Community and Social Services (MCSS) as the government funder, and submit invoices at the end of each month. This system has worked very well with the Special Services at Home Program. The Auditor-General has reported that it is a program that is very accountable.

## **Key Elements of a Person-Directed Planning Process**

Person-directed planning means that the person with the disability directs the planning and decision-making in his or her life. He or she does this with whatever means of communication they have and with the help of those they trust. Person-directed planning is a key part of individualized funding.

Planning is a life long process that gives direction and purpose to the life of the person with a disability and those he/she trusts. Planning helps the person figure out how best to use gifts and talents. The planning process is intentional about what the person wants to do, how they will do it, and what help they need from others so that

they can create a future and a 'good life' in the community. The planning process fosters the importance of engagement, companionship, contribution, and experience. It is a process that happens over time.

A good life is different for everyone. However, we know that for most of us a good life means having relationships with friends and family, contributing to community, and having plenty of opportunities to be included. The planning process will assist people with disabilities, their family, friends and others to increase the amount of choice and control that they experience in all areas of their life by helping them state and act upon the vision and goals they have for themselves. A good person-directed planning process always leads to action. It also creates the plan from which people can apply for direct individualized funding.

*"All of us plan things. Having a vision is the only way to get the life you want and need."*

*Facilitator*

## **Independent Planning and Facilitation**

Independent planning and facilitation is a support to direct individualized funding within a citizenship structure. (See Appendix C) Independent planning and facilitation is based on key principles:

1. *Person-directed* – people with disabilities are the decision-makers for their own lives (often with the help of people who care about them)
2. *Inclusion and participation* – all people need to be an integral part of their chosen community
3. *Diversity* – individuality, culture and beliefs are honoured
4. *Contribution* - each person has unique gifts and talents to share with others
5. *Relationships* – are important and need to be developed and fostered
6. *Funding* - for disability supports is individualized, flexible and portable
7. *Individual Rights* – respects the persons individual rights, entitlements and responsibilities
8. *Relational* – the facilitator develops a relationship of trust with the person, their family and network that is strengthened and developed over time
9. *Choice* – person and families have the option of using independent facilitators from a publicly funded organization or choosing their own with public funds

*10. Continuous* – planning is an on-going, flexible process.

Research is showing the importance of independent planning and facilitation. In Western Australia, where facilitators have been in place for fifteen years, this support to individuals and families has been able to reduce costs and improve community participation of people with disabilities. A recent study in Ontario showed that when people have direct individualized funding *and* independent planning and facilitation, they have very positive citizenship outcomes.

## **Access**

The *New Story* is based on fair and equitable access to disability dollars and support. Direct individualized funding needs to be supported by an allocation process that is guided by clear principles.

Access to the system and allocation of support dollars must:

- Be based on the values and principles of a citizenship based structure
- Utilize a respectful process for individuals and families
- Be an anonymous process
- Be equitable and transparent
- Be based on people’s plan and not penalize people for enhanced natural supports and community involvement
- Take into consideration the economic and emotional impact on caregivers
- Be just as concerned with “prevention” as with “crisis” and place high value on investment supports
- Have an appeal process that is user friendly, and fair.

*“We have been more efficient in providing people for services than services for people”*

*O’Brien, Lovett*

## **Accountability**

The *New Story* provides for an accountability mechanism for direct individualized funding that:

- Begins with a basis of trust and respect for people with disabilities, their families, friends and others
- Respects the knowledge and experience of the person, and those they trust to assist them - their families, friends and others
- Removes any barriers that prevent people with disabilities, families, friends, others and service providers from being creative and innovative
- Assists people to become good stewards of public funds in order that it can be used in the best possible ways
- Provides an easy manner in which to report about funding
- Is linked to outcomes that take into consideration a person's goals, unique situation and quality of life
- Ensures that accountability mechanisms are not punitive
- Is a process that is fair, equitable, and transparent, confidential and user friendly
- Allows people, families, friends and others a sense of security and continuity in their funding (See Appendix D)

## **Evaluation**

The evaluation of direct individualized funding is linked to the person-directed planning process and the goals the person has for themselves to enhance their own life in community. *New Story* evaluation provides feedback for families, communities, and government about how disability supports are working in terms of citizenship and participation.

## Building Independent Planning and Facilitation with a Community Development Approach

### Development at the Community Level

The Individualized Funding Coalition for Ontario believes that the most effective way to implement independent planning and facilitation throughout the province is to do it through a community development approach. A community development approach to transformation means that work already done in communities across Ontario will be valued and honoured. This approach would build on the demonstrated and documented success of communities in Ontario. Pockets of excellence would be acknowledged and built upon. Ontario is dotted with pockets of excellence from the southwest to the north and east! However, in some areas the community development work would be about developing something entirely new by bringing interested community partners together to plan and develop actions together for the first time.

Using a community development process would result in each community bringing forward or enhancing independent planning and facilitation in its own unique way. It would ensure there was not a government-bureaucratized system of facilitation laid on to communities. This has been a fear of the grassroots (including many people with disabilities and families) who have not wanted this function to be systematized using a standardized approach. It is important as we move forward that we get this right. We do not want to subject people with disabilities and their families to bureaucratic mechanisms that do not make sense. Instead we want to support them with a process that is family friendly and built in community.

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*It also warned of the need to proceed carefully with an innovation in the early stages of system wide implementation: Experience suggests that it is better to introduce person centred (person directed) planning gradually. Trying to create lots of person centred plans for everyone quickly is likely to lead to lots of plans but little positive change in people's lives. 4*

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Moving forward with a community development approach provides opportunities that other approaches do not:

*Individualized Funding Coalition for Ontario*

- Independent Planning and Facilitation could be phased-in in a few communities, perhaps beginning with three regions to enhance learning and development
- Communities could have the support of an Ambassador to bring people together, identify its own uniqueness, its strengths, and its vision within the values and principles of direct individualized funding and independent planning and facilitation
- Each community could be linked through forums and facilitator networks and a mentoring initiative based on best practices and the right values and principles
- A mobile workforce can be developed within a given geographical area as an outreach model of working in community to offer facilitation and planning support

The community development approach we envision relies on comprehensive training of the foundational values and principles, discovering the uniqueness and diversity of a community, identifying strengths and gaps, building capacity at the local level, intentional mentoring, and strategies to share best practices across the province.

*The essence of a community development approach to developing Independent Planning and Facilitation throughout the province is that communities have the opportunity to discover the right fit with what already exists, while at the same time being grounded in the values and principles. Support for this process could be available from a provincial steering group.*

Each community may be distinct in their approach, but will be expected to produce similar outcomes, clear functions, and a structure that can deliver Independent Planning and Facilitation. Here are some concrete examples of how different community development processes would work:

- One community may find that they have a number of value based facilitators already present in their community. These facilitators might currently work in

separate agencies. Those facilitators and some of the agencies recognize that although this has been good for people there is still an inherent conflict of interest. They would like to start working on extracting budgets and facilitators from their agencies to set-up an Independent Planning and Facilitation function in their community – outside of direct services. An Ambassador could help with bringing the community partners, including the Ministry of Community and Social Services, in that region together for discussions to begin the process of change. The outcome could involve merging of resources to create an Independent Planning and Facilitation structure that is free of agency conflict and supported by the grassroots.

- In another community, there may be a need to provide more intensive training and mentoring as well as assistance from a provincial steering group in order to develop a community plan to roll out Independent Planning and Facilitation in the community. In this community, a few groups are very interested in establishing this function, so an Ambassador meets with this small group to explore possibilities. It turns out that most of the energy for this new approach is coming from families, and two family groups step forward and take leadership. This area has a long history of family-led initiatives. With support from MCSS and some service agencies, it is agreed that a family-governed model makes most sense and a proposal is developed. The outcome could be a family-governed organization taking the main responsibility for Independent Planning and Facilitation.
- In yet another community, an Independent Planning and Facilitation organization exists, but the original design and actual operations has resulted in too many people being served as demand increased over time. An Ambassador meets with MCSS and other partners to determine how to best to grow the organization and be sure that everyone who wants this type of support has access. Several meetings take place to review the principles and process and then several recommendations are made to MCSS and the community. The outcome could be an enhanced Independent Planning and Facilitation function with broader community support.

## Outcomes at the Community Level

Over time, as a support to direct individualized funding, each community should be able to put in place:

### 1. Community building to increase the capacity and opportunity for Independent Planning and Facilitation

This process uses the strengths and abilities of each community and its members as building blocks on which to expand the capacity and interest for Independent Planning and Facilitation.

### 2. Independent Planning and Facilitation

The development of this much needed infrastructure support would ensure that effective person-directed planning with skilled facilitators, independent of the service system, are available to people.

### 3. Financial and human resource supports

This would ensure that human resource supports and financial accountability mechanisms are in place to support people who have direct individualized funding. It would assist families and individuals with hiring their own workers, providing a payroll service for support workers and more. We know that these mechanisms strengthen people's ability to utilize direct individualized funding and to act on their person directed plans.

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*We would like to dethrone measurement from its godly position, to reveal the false god it has been. We want instead to offer measurement a new job – that of helpful servant. We want to use measurement (and evaluation) to give us the kind and quality of feedback that supports and welcomes people to step forward with their desire to contribute, to learn, and to achieve. 5*

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### 4. Autonomous family and People First groups

The community development process would ensure there is a commitment to invite participation from families and people with disabilities and autonomous groups because they are an important part of

the *New Story*. Communities would be supported in their commitment to strengthening and/or develop autonomous groups in their community.

## **5. Comprehensive Evaluation Process**

This work would involve quality of life accountability for the people receiving direct individualized funding (See Appendix C). This would establish key patterns related to citizenship and community participation. It would teach us what is important to people and how we can facilitate its development. Outcomes would be gathered in the areas of relationships, community participation, etc.

## **Development of a Provincial Steering Group**

Within a citizenship structure, Independent Planning and Facilitation must be in place as a support to the direct individualized funding that people will have. Likewise, the community development approach being used to implement Independent Planning and Facilitation would need to be guided by a Provincial Steering Group to ground and support the process and principles at the community level. This Provincial Steering Group would need to be made up of various stakeholders including government, people with disabilities, and families. This collaborative approach would support the development of Independent Planning and Facilitation. As well, it would enable communities to design and implement it in a way that is grounded in strong foundational values and principles and unique to their area. The goal would be Independent Planning and Facilitation that is authentic, not a cookie-cutter approach or bureaucratic overlay across the province. This is one process that cannot be bureaucratic in nature – *it must be a collaborative process.*

We propose that an initial steering group be initiated by MCSS and be made up of leaders within and outside government who are committed to the values outlined in this paper. The role of the steering group would be to begin the development work in the areas of community preparedness, information development, and training. This provincial steering group would be put in place as soon as possible, at the beginning of the transformation process to:

- Ensure **consistency and coherency** of the values and principles into initial implementation and beyond
- Ensure that the most knowledgeable people provide the necessary upfront **leadership**
- Build a **collaborative approach** to creating change in Ontario
- Use **Ambassadors** as part of the development process
- Keep the independent **planning and facilitation roles/functions separate** from other functions in the system as part of a new paradigm
- Ensure experienced facilitators provide solid **training** to ensure success
- Facilitate and monitor **overall implementation** and ensure they do not become bureaucratic in nature or go off the track.

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*"We have to change the way we think, We have to move to a philosophy, a culture, rooted in person capacity, valuing people for their contribution; to an asset based, and closer-to-community approach. This means changing our thinking so we are providing support that will enable individuals to contribute to their community based on their assets rather than providing services based on their deficiencies." 6*

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### **The Main Functions of a Provincial Steering Group**

A provincial steering group function would be needed to:

- Hold and promote the values and principles of Independent Facilitation within a citizenship, self-determination, empowerment framework where participation, inclusion and building capacity are paramount
- Offer strong value-based facilitator training based on experience, knowledge and connectedness around the province. Although some training and coaching would be provided locally, much of it will be provincially based to ensure that the values and policies are implemented across the province
- Enter into contractual arrangements locally/regionally with local capacity. We could call this 'contracting with the best there is locally' using criteria determined by the provincial steering group

- Provide community development leadership in those communities that need to build their capacity for this function
- Promote and enhance the varied roles of independent facilitation
- Support a provincial facilitator's forum, virtual networks, and geographical networks of facilitators to support each other in their work
- Encourage best practices in governance. This would include models where people and families are the majority on the board or steering committee. There are other examples of best practices to draw from, including family governed advisory boards, boards with people and families, and community representation as well.

### **Changing Roles for Service Providers**

Direct individualized funding supported by Independent Planning and Facilitation will cause changes in the way we support people with disabilities, their families, friends and others. Service providers and the services they provide will be affected by the transformation of developmental services. Over time their thinking and practices will begin to shift and become more consistent with the *New Story*.

As well, over time service agencies will respond with innovative ideas and more person-directed approaches. They will begin to:

- Develop processes that increase participation and engagement **7**
- Invest in staff training, board leadership, individual and family involvement
- Create principles that move people toward the *New Story*
- Create organizational strategies, functions and structures that are coherent with each other and with the *New Story*
- Begin to focus on what they do well
- Become effective at responding to people who have person-directed plans and people that have direct individualized funding.

## **A Vision for the Future: Real Transformation of Developmental Services**

The Individualized Funding Coalition for Ontario has a vision for the future. Our vision is invested in the possibility of real transformation of developmental services. Such transformation will emphasize choice, give people with disabilities and their families control over their own lives, build in needed infrastructure supports, and move us closer to citizenship for all members of our communities. Real transformation will require a comprehensive and multi-layered approach to the implementation of direct individualized funding and the needed infrastructure supports including independent planning and facilitation. A piecemeal approach will only result in more frustration, more failure, and add to the broken promises that people with disabilities, their families and networks often experience.

The Ministry of Community and Social Services must take the lead on the development of a policy framework as well as roll out a clear implementation strategy that has been developed within a community framework. We envision MCSS and local communities planning and working together to ensure that the promised transformation of developmental services is delivered in Ontario. This transformation must build on the strengths and abilities of the people, services, and infrastructures that already exist in each local community. People with disabilities, their families and networks must be an integral part of the planning, implementation, and evaluation process. The transformation of developmental services must include the learnings and research from other places, ongoing research, and be focused on good process as well as outcomes. Transformation must become an ongoing learning process.

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*It is not a single technique but a 'family' of approaches that, collectively, give people with disabilities along with their families, and networks control over their own lives and allows for them to use their gifts and talents in order to contribute to their communities. A good facilitation process along with access to individualized funding and support enables life to unfold in many interesting ways.*

Facilitator (2006)

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Real transformation of developmental services is possible if together we explore the present barriers that exist and the possible bridges that can be built for this desirable future for people with disabilities, their families and networks.

## **Culture**

*Present* – Services are now predetermined and people fit into the services as offered which can lead to the wrong services and action for people.

*Future* – we envision a culture of supports that is guided by a person-directed planning process, supported by an independent facilitator. This planning process with expressed goals will inform the development and delivery of services. This is a shift in thinking and a shift in the balance of power.

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*People with disabilities need direct supports as well as increased opportunities to participate in learning, work and community life. Partners must work together to address issues facing Canadians with disabilities and their families, in order to promote full participation and improve quality of life in the long term. 8*

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## **Policy and direction**

*Present* – while direct individualized funding and independent planning and facilitation has been highlighted in *Opportunities and Actions*, there have been no policy changes nor has there been an implementation plan put in place to ensure the needed infrastructures become reality. There is an over-reliance on the part of government to depend on the present developmental service system to shift people's thinking and actions.

*Future* – direct individualized funding is supported by a systemic approach to independent planning and facilitation as well as the needed infrastructure support such as human resources and administration support. Agencies are able to focus on providing person-directed approaches to their services and supports.

## **Resources**

*Present* – base budget funding allocations prevent the development of person-directed approaches. Current disability support dollars are attached to programs, beds and spaces, rather than to people, plans, needs and goals. The current examples of direct

individualized funding initiatives are often 'rolled out' without consideration for the planning and facilitation support needed.

*Future* – we envision a change in the way that funding is allocated and used. Direct individualized funding to the person, their family, network or designate will enable services to be designed and delivered to meet the needs and goals of the person. Portability allows for more choice and control when supported by person-directed planning and related infrastructure supports.

### **Capacity Building**

*Present* – the lack of skills and training in *New Story* approaches prevent front-line and management staff from being able to respond to requests for services from those who have chosen direct individualized funding as an option. There is also a lack of qualified independent facilitators available at the local level.

*Future* – there is wide-spread training and opportunities for staff to learn about the *New Story* and individualized approaches. There is an investment in providing good quality facilitation training. All training is building on the gifts and capacities that already exist in community.

### **Decision Making**

*Present* – there is little experience in sharing decision-making with the person, their family and network. Staff people are often viewed as the decision-maker in a person's life. They often experience conflict in their role as a decision-maker and service provider.

*Future* – decision-making rests with the person along with their family and network. They have the assistance of an independent facilitator in exploring and voicing their hopes, needs and goals. They have full say in design and monitoring of the services and supports they receive.

### **Independence**

*Present* – person-centred planning is often part of a developmental service delivery model. This 'in house' planning leads to an over-reliance on services and does not utilize community options to its fullest potential.

*Future* – person-directed planning processes are guided by independent facilitators who are located separate from the support services provided by developmental service agencies. The person directs in their own way as he or she participates in the process. Local independent planning and facilitation avenues would be supported by a provincial steering group.

## **Implementation**

*Present* – too many people have engaged in a planning process but there has been a failure for those plans to lead to action.

*Future* – ‘person directed planning always leads to action’ is a cornerstone philosophy of independent planning and facilitation.

## **Citizenship**

*Present* – people with disabilities tend to move through community from program to program. They have few relationships outside of services. Services are approached from a group and program perspective.

*Future* – people with disabilities will move towards citizenship. They have assistance to build and maintain relationships, participate and contribute to their communities, and lead a life of their own choosing that is supported by the people and services that makes sense to them.

The time has come to ensure that the vision put forth in *Opportunities and Action* comes to fruition. A vision is just that unless it is supported by the structures needed for action. We envision an Ontario that includes direct individualized funding, independent planning and facilitation, and other necessary infrastructure supports within a citizenship structure. Ontario has the capacity to develop a “Made in Ontario” transformation of developmental services. The time is now! People are waiting!

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“You must be the change you wish to see in the world.”

Ghandi

## **Endnotes**

1. For a summary of IF research, see John Lord and Peggy Hutchison (2003), Individualized support and funding: Building blocks for Capacity Building and Inclusion. *Disability and Society*, 18:1, 71-86. Also see Tim Stainton (2005), *Individualized Funding*, Presentation to Policy Forum of Ontario Ministry and Community Services, March 30. For further research on IF and self-determination, see Roger Stancliffe & Charlie Lakin (2005). *Costs and Outcomes of Community Services for People with Intellectual Disabilities*. Baltimore, MD: Paul H. Brookes Publishing.
2. John Lord. *Moving Toward Citizenship: A Study of Individualized Funding in Ontario* Toronto: Individualized Funding Coalition for Ontario, 2006.
3. Individualized Funding Coalition for Ontario. *Creating a Good Life in Community: A Person-Directed Planning Guide*. Toronto: Individualized Funding Coalition for Ontario, 2006.
4. Ministry of Children and Family Development, British Columbia. *Discussion Paper on Community Living Services*, October 2001. 7.
5. Margaret Wheatley. *Finding Our Way: Leadership for an Uncertain Time*. San Francisco: Barrett-Koehler, Inc, 2005, p. 162
6. Institute for Health Research. *The Impact of Person Centred Planning*. England: Institute for Health Research, Lancaster University, April 2005
7. Taken with permission from a presentation by Dr. John Lord (John Lord and Associates)
8. Government of Canada. *The Strategic Plan of the Office for Disabilities Studies 2002-2007* (Government of Canada)

Appendix A

**Evolution of Our Service Response to  
People with Disabilities**

	Institutional Service System	Community Based Service System	New Story Approaches
The Planning Focus	Development of a treatment plan or plan of care.	Development of a program or service plan.	Planning Process is directed by the person with their network and support of an independent facilitator.
Decision Making	Staff including in-house psychiatrists, therapists, frontline staff and supervisors.	Staff, family and sometimes the person but in the context of services and programs offered.	The person and their network.  Relationships of their own choosing that the person can count on.
Funding	Government operated and funded.	Transfer payment agencies. From government to non-profit agencies.	Individualized, direct, portable and flexible funding to the person and their network.
Primary Support	Emphasis on treating, fixing or teaching the person.	Support to group defined by a program or support to a person but attached to housing.	Individualized supports are based in community and are unique, and responsive. Supports are individualized to meet the need of the person, not program driven. Housing and supports are de-linked.
Underlying Belief About the Person	Needs protection, treatment, and maintenance. Not capable of life in community.	Has strengths and deficiencies. Focus on changing. Belongs in groups of "own kind".	Citizenship is for everyone. Everyone has talents, gifts, and abilities that can be shared with others. Everyone can be contributing members of their community.
Outcomes	Separation from family and community.	Person has life in service. Moves through community from program to program. Few relationships outside of service.	Life is in community. Participation and contribution are evident. People have meaningful and valued roles and relationships.

## A Framework for Individualized/Direct Funding

### Moving toward full citizenship: A Separation of Functions\*

#### INDEPENDENT Planning & Facilitation

*Independent of direct service delivery; Independent of access centres; Independent of funding allocations; Value based; Strengthens and empowers people, families and support networks; Leads to community participation and contribution*

#### ALLOCATION DECISIONS

*(Application with Plan and Priority Panel Processes)  
Accessible; Equitable; Allocations by government that are flexible, responsive to changing needs and fully portable; Shifts control to the person, family and support network.*

#### AUTONOMOUS GROUPS

*(People First Chapters and Family Networks/Groups)  
Offer leadership in innovation and education; Peer support; Advocacy; Provide a balance in the system and can safeguard new approaches with their voice*

#### SERVICES AND SUPPORTS

*Infrastructures that provide coordination of human resource support, financial accounting and capacity enhancement (i.e. teaching families, personal assistants). Person with their support network decides where to purchase this service (i.e. from the community at large and/or service providing agency)*

**\* Note:** Moving toward full citizenship for all requires a framework that keeps the following functions separate: planning and facilitation; allocation; direct service; peer support/advocacy. This framework is different than a more traditional one where all these functions have historically occurred within one direct service providing agency or system. With an individualized/direct funding approach, having the options of: 1) independent planning and facilitation; 2) connecting with autonomous groups; and 3) purchasing direct supports as determined by the person with family and support network would lead to success.

#### Priorities for Moving Toward Full Citizenship

- providing information to people and families that brings awareness of more options
  - shifting control to individuals/families/support networks
- ensuring exposure to more life choices and increasing quality of life
  - building capacity in individuals, families and community

## **Appendix C**

Our Vision for a

# **Direct Individualized Funding Approach in Ontario**

*Developed by the Individualized Funding Coalition for Ontario  
at the membership meeting of June 15, 2006*

## **BACKGROUND: Direct Individualized Funding**

**Individualized funding** provides the means for a person to meet their individual goals by determining what supports will be purchased with funding designated to them and by directing those supports. **Direct funding** is a way of managing individualized funding. It is funding that **goes directly to the person/family/network**. It is the approach that the Ministry of Community and Social Services is using for Passport.

## **THE IFCO VISION**

### **1) Direct Individualized Funding that is based on the following values:**

- Citizenship
- Inclusion
- Self-determination
- Community
- Supports for a whole life, a look at the whole person

### **2) Direct Individualized Funding that is based on the following principles:**

- The person/family/network are the decision makers with the person's voice being honoured in the process
- Participation and contribution in community is a given – community as a first resource
- Dreams of the person and the strengths of the person, family and support network guide the process
- Planning and facilitation is a separate function in the system
- Relationship building and networks of people are key
- Funding is fully portable (can be moved within an area to a different agency, to another part of the province, out of province, from agency base budgets to direct, whatever is needed)

### **3) Direct Individualized Funding that has infrastructure support options in place for people to experience success, including:**

- 1) Independent Planning and Facilitation
- 2) Services and Supports that are especially designed for direct individualized funding as follows:
  - Invoicing/financial accounting and accountability
  - Human resource support
  - Capacity enhancement, i.e. training for families and personal assistants

## **INDEPENDENT PLANNING AND FACILITATION**

### ***In the IFCO Vision, Independent Planning and Facilitation:***

- Is separate from direct service provision
- Is separate from access centres (single point of access)
- Is separate from funding allocation
- Is an infrastructure support to Direct Individualized Funding
- Has a relationship with a provincial group that holds the values and offers value based training.

### **Roles of an Independent Facilitator**

The role changes throughout the planning process. People will call on the facilitator as needed for various things. The varied roles include:

- Getting to know the person well
- Building relationships with the person, their family, network, and the local community
- Listening deeply - people say things in many different ways
- Providing information
- Linking with others (family networks, People First etc.)
- Networking and relationship development, **building of support networks**
- Facilitating with the planning process
- Facilitating community connections in both formal and informal settings
- Building on the strengths, capacity and self-determination of the person in order to create a good life
- Community development
- Recognizing people, their families and networks as decision makers
- Ongoing Monitoring/Evaluation with the person and their family/network
- Brokering Roles:
  - Negotiation
  - Mediation
  - Third Party Document/Contract writing

***Developed by the Individualized Funding Coalition for Ontario, June 15, 2006***  
*Revised November 2006 using phrase 'Direct Individualized Funding' to reflect MCSS direction.*

## **Appendix D**

# **Individualized Funding and Accountability**

## **Financial Accountability**

Proponents of the *New Story* recognize the fact that people, along with their families, or designate want a simple and effective way in which to be good stewards of public funds.

1. For payment of direct individualized funding, the person their family, network or designate will meet the standards set for the current Special Services at Home program in regard to management of funds, monitoring, and reporting of expenditures
2. The person, their family or designate will have a responsibility for safeguarding the public funds
3. MCSS will set standards of financial accountability that ensures that the funds provided to the person, their family, network, or designate are used for the intended purposes
4. MCSS will implement an invoicing system which allows for timely monthly invoicing, and monthly allocation of funds
5. The person, their family, network or designate will establish and maintain an accounting system that satisfies the needs MCSS has for specific information
6. All financial records will be available for the scrutiny of MCSS upon request.

## **Quality of Life – Monitoring and Accountability**

The *New Story* provides for leadership to envision a better quality of life for people with disabilities, their families and networks.

1. **Goal setting**, intentionality, and adequate funding contribute to well being, contribution, and inclusion. To determine the quality of life in this instance looking at whether the person is doing what they want to be doing, is meeting his/her goals, is contributing and being included is important. Whether others are doing what they said they were going to do to ensure the person's goals and life is full is also important, this would include: support workers, facilitator, direct service provider, etc.

2. **Relationships** and the support to build and maintain relationships contribute to safeguarding well being. Are those relationships that are most important in the person's life coming together as needed to continue planning and brainstorming or to solve issues as they arise? Does the person have opportunity to develop new relationships in the community? Does the person already have some ongoing relationships – like colleagues where he or she volunteers, at the restaurant visited regularly, etc.?
  
3. **Community Presence** and providing opportunities for contribution, growth and learning contribute to increased self-worth, importance and valued social and economic roles. Is this person participating and being included in things? Are they the things this person wants to be doing?