

**Linking Individualized Supports  
and Direct Funding**

**Making Money Work for People**

A PATHWAY TO SELF-DETERMINATION  
AND COMMUNITY INVOLVEMENT  
FOR PEOPLE WITH DISABILITIES

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Report of the  
Ontario Round Table  
on Individualized Funding

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May, 2000

## **Report of the Round Table on Individualized Funding**

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## The Round Table on Individualized Funding

was sponsored by the

## Ontario Coalition on Individualized Funding

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## PREFACE

### **Purpose**

The purpose of the Round Table on Individualized Funding was:

*To develop province-wide principles, a policy framework, and directions for Individualized Funding, and to identify strategies for implementation.*

Round Table members represented sectors of our society who are interested in creating disability supports that are flexible and responsive to the person receiving support. All members had experience with individualized funding, whether as an individual with a disability, family member, advocate, researcher, broker/facilitator, or service provider.

### **Process**

The Round Table began its work by examining research and practice related to individualized disability supports. We looked at Ontario pilot projects related to individualized funding, and studied existing direct funding initiatives in Ontario, Alberta, British Columbia, Western Australia, Great Britain, and the United States. Based upon this analysis, we discussed what is considered “best practice” in the provision of individualized disability supports. We discovered that the most common outcomes associated with “best practice” are self-determination and community involvement. With this in mind, we then drafted principles to guide policy, planning, and programs. Based on the principles, and a synthesis of knowledge gathered from research and “best practices,” we built a policy

framework. Our final task was to consider the implementation issues. For each set of issues, we have identified directions and strategies.

As a companion document to this Round Table Report, the Review of Individualized Funding provides extensive background information and research on projects and policies that enhance individualized support and funding. We express our thanks to the Ontario Federation of Cerebral Palsy for sponsoring the Review, and sharing the findings with us.

### **Recommendations**

We have three main recommendations;

- 1. That the Ontario government adopt the principles, policy framework, and implementation directions of the Round Table.*
- 2. That the Ontario government work closely with citizens and stakeholders throughout Ontario to implement the principles, policy framework, and implementation directions.*
- 3. That community organizations involved in providing disability supports work with other groups in their communities to implement the principles, policy framework, and implementation directions of the Round Table.*

There are currently programs and policies in Ontario that provide direct funding to individuals with disabilities, but these programs and policies are very limited. It is time to ensure that any citizen with a disability is able to access the option of direct funding. We submit this report in the hope that this work will contribute to building this future.

## A Round Table Conversation

January 24, 2000

**TIM MARMURA & BETH KOMITO-GOTTLIE**

Beth: Tim, what is different about your life now that you have some individualized funding?

Tim: I have more people to help me get out in the world.

Beth: Didn't you have friends and support before?

Tim: There was no sort of schedule before – no sort of team before.

Beth: How do you think having more of a team (support circle) and a schedule affect you?

Tim: It helps me to feel life has some kind of expected pattern.

Beth: You mean life is more predictable?

Tim: No, it has more consistency.

Beth: What's the difference?

Tim: It means my life has a constant routine now.

Beth: Knowing you as I do, I get that, but for other people, Tim, why is a consistent routine important to you?

Tim: I can know what to expect and what I will encounter.

Beth: There are more activities in your life now as well. Can you talk about them?

Tim: I am doing more, like the food bank, No Frills, swimming, reflexology, music, and the dialogues with Joey and Joel.

Beth: To do all of these things means many people need to be helping and planning. Can you talk about what this means to you?

Tim: I feel good that the team meets to talk about how to help me even though I don't like to go because it is too stressful for me...I need more people now that I am getting out more. I need a social life and to meet more new people.

## **INTRODUCTION**

The Round Table on Individualized Funding in Ontario was developed to design principles, a policy framework, and implementation directions that could enhance a system of individualized disability supports, including the option of direct funding. Members of the Round Table have examined the extensive work that is currently going on throughout Canada and several other western countries. This research shows that direct funding to citizens who require disability support is an effective approach to enhancing self-determination and community involvement.<sup>1</sup> The work of the Round Table is very timely, given that more and more individuals, service providers, and governments are expressing interest in approaches that expand choice and control for citizens with disabilities.

### **Current Context and Dilemmas**

Almost one of every five citizens in Ontario have conditions of some sort that affect their abilities to live in the community in ways the rest of us

take for granted. People with disabilities need supports of various kinds to ensure a decent quality of life. Some people can cope with adaptive aids or with help from community health services. Others may need intensive help from paid support staff. Many citizens with disabilities require support to be able to participate in community life. The reality is that people with disabilities are often limited in their capacity for citizenship because disability supports are inadequate, inappropriate, or unavailable. Federal and provincial governments have recognized that citizenship should be central to the way we organize disability supports.<sup>ii</sup>

Disability support may take various forms. For a citizen with a physical disability, support could include an attendant who assists the individual with meal preparation and personal care. For a citizen with a developmental disability, support could include a worker who assists with money management or communication. Increasingly in Canada, disability supports are seen as separate from income supports. It is widely recognized that both disability supports and income supports are required to enhance the citizenship and quality of life of people with disabilities.



In traditional approaches to policy and the provision of disability supports, congregate programs and block funding to community agencies have guided policy and practice. Such approaches have worked well for some people. However, many disability groups have been demanding more individualized approaches to the provision of disability supports.<sup>iii</sup> The concern relates to the fact that access to disability supports is often restricted to formal agency programs for which there are generally very narrow criteria. Furthermore, citizens with disabilities in Ontario often do not have access to disability supports, which are congruent with their degree of disability and the level of support they may require. Services also vary widely, based on many factors, including geography and circumstances. For example, many adults with disabilities returning to our communities from institutions have received reasonable and sufficient support funds, while hundreds of individuals who have always lived in the community have been unable to access support dollars.

Research shows that people with disabilities are less likely to be employed, more likely to be poor, and often have limited social support. These factors contribute to vulnerability and poor health.<sup>iv</sup> The growing demands on current service systems often makes it impossible for people

with disabilities to receive the supports they require to address these significant issues. As demographics shift, more and more people with significant disabilities are living in the community. Among younger families, children with disabilities have increasingly been able to experience inclusion and participation in schools and community. All of these factors point to the importance of developing more options for adults with disabilities and their families to access individualized disability supports.

### **The Emergence of Individualized Disability Supports**

During the last twenty years, numerous jurisdictions have been exploring alternatives to the traditional agency driven approaches. As already mentioned, the focus of these alternatives has been on the self-determination and community involvement of citizens with disabilities. The newer approaches are characterized by more individualized supports. An individualized approach applies to the way the person plans, to the way the person receives support, and to the way the support is funded. Each person is seen as a unique individual, with his or her own goals, strengths, preferences, and needs.

The development and implementation of more individualized disability supports builds on initiatives already undertaken by the Ontario Government. The Direct Funding Project within the Ministry of Health and Long Term Care in Ontario, for example, allows adults with physical disabilities who are able to direct and manage their own support, to receive money directly for their disability supports. This program supports one of the Ministry's goals, which is to provide support services to enable people with physical disabilities to live independently.

The Ministry of Community and Social Services has the mandate to provide an affordable and effective system of community and social services that supports and invests in:

- families and communities, to encourage responsibility and accountability;
- adults, so they can live as independently as possible.

MCSS goals and initiatives emphasize client-focused services. In their document Making Services Work for People, several goals are noted, including;

- families and individuals will receive services to meet their needs.

- families and individuals will be served by local systems that make the best use of local resources.

In keeping with the above mandate and goals, during the last few years the Ministry of Community and Social Services sponsored several pilot projects that have utilized individualized funding for citizens with developmental disabilities. Projects in Mississauga, Toronto, Thunder Bay, and Windsor have been particularly instructive. There are many lessons from this work in regard to the key elements that can guide an equitable, effective direct funding program.<sup>v</sup>

Our analysis of projects and programs that facilitate individualized disability supports suggested that an important paradigm shift is occurring within the disability field. Phrases such as “person-directed planning,” “individual and family control,” “community connections,” and “network building” reflect the paradigm shift. Direct funding of disability supports is viewed by many in the field as a mechanism for ensuring that the paradigm shift is grounded in genuine options for individuals and families. These options now exist in some Ontario communities and for selected

populations. To build a more comprehensive, inclusive approach, the Round Table recognized the need to start with principles to guide such a system.

## **PRINCIPLES TO GUIDE POLICY, PLANNING, AND PROGRAMS**

Principles provide a set of guidelines for how we want to live our lives. In a recent review of programs that utilize direct funding for the provision of disability supports, it was found that almost all initiatives had clearly stated values and principles.<sup>vi</sup> The following principles were developed by the Round Table. They are consistent with principles articulated by successful projects around the world, and they emphasize individual and family control, self-determination and community involvement.<sup>vii</sup> *We recommend that any new policies or programs related to disability supports be guided by these principles.*

### **General Principles of Disability Support**

1. Rights and dignity – All people with disabilities should be respected for their human worth and dignity, and have the same rights and responsibilities as other community members.

2. Community capacity and inclusion - Individualized planning, support, and funding should facilitate natural, informal support (family and friends) and be designed to enhance citizenship, community capacity and inclusion.
  
3. Freedom and choice - People requiring support because of disability should have the freedom to plan their own lives and to receive the supports that are necessary for a reasonable quality of life.
  
4. Information and self-determination - Each individual and their support network (including family and friends) should receive accurate and timely information, and be able to control how supports are provided and how funds are utilized.
  
5. Personal relationships and contributions – Each person should have social roles that involve personal relationships, participation in the community, and opportunities to contribute. These domains are critical to reducing the vulnerability of people with disabilities and safeguarding quality of life.

## **Principles Specific to Individualized Planning, Support, and Funding**

6. Individualized and personal – Planning and support should be directed by self-determined decisions and preferences. Planning is based on in-depth knowledge of the person, and support and funding reflect the unique circumstances of each individual.
7. Formal and informal support – Planning and support should include both formal and informal support. Formal support is paid support, with the person and their network determining whom they will hire. Informal support includes family, friends and others in the network of the person.
8. Direct and portable – Funding should be dedicated to an individual. The person and/or their designate have control over the funds and choose how the money is to be administered. Funding moves with the person; people with disabilities may live and work where they choose.
9. Flexible and adaptable – The individual should have the flexibility to choose direct funding as a primary option. Support and funding is adapted to the changing needs and preferences of the individual.



10. Continuous planning and implementation support – Local planning for the individual should be unencumbered, and kept separate from service provision. Infrastructures, such as facilitators, are in place to assist individuals and their networks to plan and access their supports.
11. Adequate and secure funding and support – People with disabilities should receive sufficient funds to purchase the supports they require.
12. Responsibility and accountability – People who receive funding should be expected to account for their expenditures. People who provide support are accountable to the person they support and their networks.
13. Responsive and available – Support workers and services required by people with disabilities should be cultivated in local communities. These workers and services are responsive, adapting their support under the direction of the person receiving support and/or the person's network.

These principles serve as the foundation for a policy framework. Research shows that principle-centred organizations utilize their principles in an ongoing manner.<sup>viii</sup> The principles become a reference point for planning, policy development, problem solving, and implementation. This is the grounding from which we present this framework for linking individualized supports with direct funding.

## TOWARD A POLICY FRAMEWORK

A policy framework is a template, set of guidelines, or direction statements that expresses the ideas and priorities of a government, organization, or community. Policy frameworks can be very broad and encompassing, such as the Canada Health Act, which sets out several principles for medicare in Canada. Policy frameworks can also be quite specific, such as the Putting People First policy in Ontario, which sets out specific principles and critical aspects of deinstitutionalization in mental health.

The Round Table has developed a policy framework to ensure that more adults with disabilities can access individualized disability supports. This framework does not necessarily require specific legislation, because several pieces of legislation provide the necessary legal mandate for this policy change. Given the number of existing programs and jurisdictions that mandate or allow individualized support and funding, there are numerous ways that the policy could be implemented. A sound policy framework will

provide the direction, coherence, functions, and structures for full implementation of the principles throughout the province.

The principles and policy framework described here can apply to government policy as well as to communities and organizations that are shifting toward individualized disability supports. In fact, coherence between policy and practice at provincial and local levels will be ensured as more and more communities and organizations embark on this process.

An Ontario policy framework for disability supports that enhance self-determination and community involvement needs to;

- build on existing policies that mandate individualized disability supports, and
- create new policy guidelines to insure there are comprehensive individualized disability supports throughout the province.

### **Current Ontario Policy and Program Options**

As already noted, there are currently several policies and programs within Ontario that mandate, allow, or encourage individualized disability

supports, including direct funding. None of these initiatives provide a comprehensive policy, but several elements of a policy framework are present within existing policies and programs. We shall briefly review these policies.

*In Unison: A Canadian Approach to Disability Issues* sets out a blueprint for promoting the integration of persons with disabilities in Canada. This document was a signed agreement in 1998 between the provinces and the federal government. The Ontario government and the voluntary sector are both now looking at the policy and program implications of *In Unison*. This agreement, which is a good fit with the principles developed by the Round Table, emphasizes five policy directions;

- policies and programs that promote greater access to supports.
- policies that separate access to supports from eligibility for income and other programs.
- policies that enhance more consumer control, flexibility, and responsiveness in the provision of disability supports.
- measures that provide greater assistance for disability costs.

Within the Ontario Ministry of Community and Social Services, there are regulations that provide for individualized disability supports and direct funding. Under the *1994 regulations of the Ministry of Community and Social Services Act*, grants can be provided directly to persons with disabilities for attendant services. In most instances, these regulations have been used to give grants to agencies that provide attendant services or personal supports. The principle of self-determination is central to these regulations, with the expectation that the individual with a disability will direct his/her own support.

As noted, the *Direct Funding Project* in Ontario is one important example of a policy and a program that implements several of the Round Table principles. It is funded under the Long Term Care Act of 1993, now administered by the Ministry of Health and Long Term Care. Adults with physical disabilities can receive funds directly to hire their own attendants. The program has been highly successful for people who can self-direct. It is important to note that there is no parallel program for people who do not self-direct. A broadened set of regulations under the *1994 regulations of the Ministry of Community and Social Services Act* would create a more inclusive policy, and allow for programs where people who cannot self-

direct could access direct funding for support workers. The Direct Funding Project does not specifically provide person-centred planning, networking and individualized supports to enhance community involvement, elements that would be required for any program that was to serve people who cannot fully self-direct.

The *1991 Guidelines for Special Services at Home* provide for individualized support and direct funding for families to enable children with disabilities to live at home and avoid institutionalization. In the 1994 evaluation, families indicated they appreciated the program because they had participation and control in the way their disability support was utilized. However, there are significant limitations of the SSAH program, including the fact that it does not have provisions for individualized planning, and does not adequately address changing support needs of individuals and families. There is wide variability across Regional Offices in terms of application. Also, SSAH does not apply to adults with disabilities, unless they have a developmental disability and live with their family.

In 1997, the Toronto Area Office of MCSS spearheaded a project to learn about individualized funding. Following a three-year pilot project run

by Family Services Association (FSA), the *Individualized Quality of Life Project* will become a new, permanent individualized program in the fall of 2000. In this project, facilitators play a major role in person-centred planning, building networks, and supporting integration and participation of individuals. Funding is individualized, but not direct, as FSA must also be responsible for adjudication and funding allocations. This kind of project points to the need for infrastructure support, including facilitation, for individuals and their networks, as part of the planning and implementation of individualized disability supports.

The *Ontario Integrated Services for Children* is responsible for integrating services for vulnerable children across several Ministries. In addition to policy development, Integrated Services develops accountability frameworks and funding mechanisms that will facilitate integration of services at the community level. All regional programs must offer families with an autistic child the option of direct funding to purchase services. Guidelines are currently being developed for this option.

Increasingly, policies and programs in Ontario are offering individualized supports and direct funding. However, most of the guidelines



attached to these policies are quite narrow, and the programs tend to have very limited capacity. There are almost no opportunities, for example, for adults who cannot self-direct, to access direct funding for disability supports. Both Ontario Ministries of Health/Long Term Care and Community and Social Services offer individualized funding in some contexts for some people. As outlined, these programs and policies have some redeeming qualities. *The Round Table has concluded that it is now time for a policy in Ontario that creates a framework for a new, inclusive approach to direct funding for any citizens with a disability who want to chose this option.*

### **Policies in Other Jurisdictions**

Several other jurisdictions within Canada, Australia, United States, and Great Britain have been developing policies and programs to enhance self-determination and community involvement. The trend clearly is to develop policies and programs that are individualized and that provide direct funding.

In *Alberta*, individualized funding has been in place since the mid-1980's. In 1990, it became the official way for service delivery. Financed

and administered under the Social Services Act and the Persons with Developmental Disabilities Act, there are detailed guidelines for two separate programs, one for people with developmental disabilities, and the other for adults with physical disabilities. Many of the principles guiding the programs are consistent with the Round Table principles, and direct funding is available to address a wide range of needs. However, there has been almost no infrastructure support for families and individuals, and unencumbered planning is rare. These have turned out to be significant weaknesses.

In *Great Britain*, the 1996 Community Care (Direct Payments) Act allows people with disabilities to receive direct funding so they can make their own support arrangements. The funding occurs through the Local Authorities, which are similar to the Community Care Access Centres in Ontario. Individualized planning is separate from services and from the process of adjudicating and allocating funds.

*Western Australia* is the first of Australia's six states to adopt individualized funding. It has one of the simplest yet highly developed approaches to individualized planning and direct funding. Based on the 1993

Disability Services Act, Local Area Co-ordination was developed to increase the self-reliance of people with disabilities. With values and principles consistent with those of the Round Table, planning is completely separate from services. Resources put into infrastructure supports and planning for individuals and families have led to very positive outcomes. Local Area Co-ordination has access to two kinds of funding – tied and untied – that enable co-ordinators to address the immediate support issues of individuals and families. The Western Australian program allows direct funding to be used for a range of supports.

### **Summary of Lessons Related to Policy**

In the course of Round Table discussions on policy, some general lessons and observations emerged from our policy analysis:

- In some jurisdictions, adults with disabilities can choose individualized planning and direct consumer funding as the primary way they obtain their disability supports.
- There are several discrete Ontario individualized funding programs that have strengths in some areas and weaknesses in others.

- Few initiatives have coherence between policy, principles, and practice. Coherence means you can see and experience consistency at all levels. For example, in Western Australia, principles are understood and experienced in policy, implementation directions, and practice.
- Many programs in Canada are not based on policy, but have emerged from pilot projects and local initiatives. Successful programs in Great Britain and Australia are based in policy and legislation, as is the Direct Funding Project in Ontario.
- The intentional separation of individual planning from service delivery is a characteristic of many policies and practices, pointing to the need for facilitation support for individuals and families.
- The most successful policies and programs have a blend of infrastructure supports for individuals/families, an individualized funding mechanism, and a well understood approach to accountability.
- It is important to look at building community capacity for inclusion, and this has not been adequately addressed in most policies and programs.
- There must be safeguards during the time of system transition, when people may choose to withdraw their supports from the service system. Only a few projects have paid attention to this issue.

- Direct funding initiatives that have had the most coherence and sustainability have been new programs. When the option of direct funding is linked or tied to service reform, too many vested interests can limit the change. Policies need to allow for new options and new programs.

### **Components of a Policy Framework**

A policy framework related to individualized approaches and direct funding should reflect the need for comprehensive disability supports throughout the province of Ontario. Our research and analysis indicates there should be five major components to the Policy Framework;

- principles
- infrastructure supports for individuals and families
- a mechanism for direct funding
- a well understood, simple approach to accountability
- a mechanism for individuals to transition to this approach.

### **Policy Framework**

<b>Principles</b>	<p>The Round Table principles should form the basis of policy, programs, and practice.</p> <p>The principles should be comprehensively applied, so that all citizens with disabilities have the option to access individualized approaches and direct funding.</p>
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<p><b>Infrastructure Supports for Individuals and Families</b></p>	<p>Infrastructure supports for individuals and families must clearly be separate from the service system.</p> <p>Infrastructure supports should include provision of information, person-directed planning support, network building support, and ongoing implementation support, including payroll and administrative support.</p> <p>Facilitators should be available to get to know the person and act in a principle-centred way with individuals and families.</p>
<p><b>Mechanism for Direct Funding</b></p>	<p>A funding mechanism that enables individuals and their families to purchase supports of their choice should be available.</p> <p>It is preferable for government to provide the direct funding, so that community structures can focus on planning, community development, and service delivery.</p> <p>Eligibility criteria should be simple and clear, and there should be no arbitrary caps on support expenditures.</p> <p>Each person applying for funds should submit a detailed plan for their use of the direct funding.</p>
<p><b>Well Understood, Simple Approach to Accountability</b></p>	<p>Individuals should have the option of self-managing their own support funds or delegating that responsibility to another person or group.</p> <p>When the individual with a disability is unable to self-manage, a designate or representative will be appointed to have the responsibility on the person's behalf.</p> <p>Accountability requirements should be as simple and streamlined as possible.</p>

	<p>Individuals and families must be accountable for all expenditures they use for disability supports. Payments should either be up front or after expenditures, with receipts being essential for both approaches.</p>
<p><b>Safeguards for individuals to transition to an individualized approach.</b></p>	<p>Individuals who currently receive support through a formal agency should be able to remove resources designated on their behalf from that setting.</p> <p>One-time transition monies should be available to assist agencies in supporting this personal and system change.</p>

## **ADDRESSING IMPLEMENTATION ISSUES**

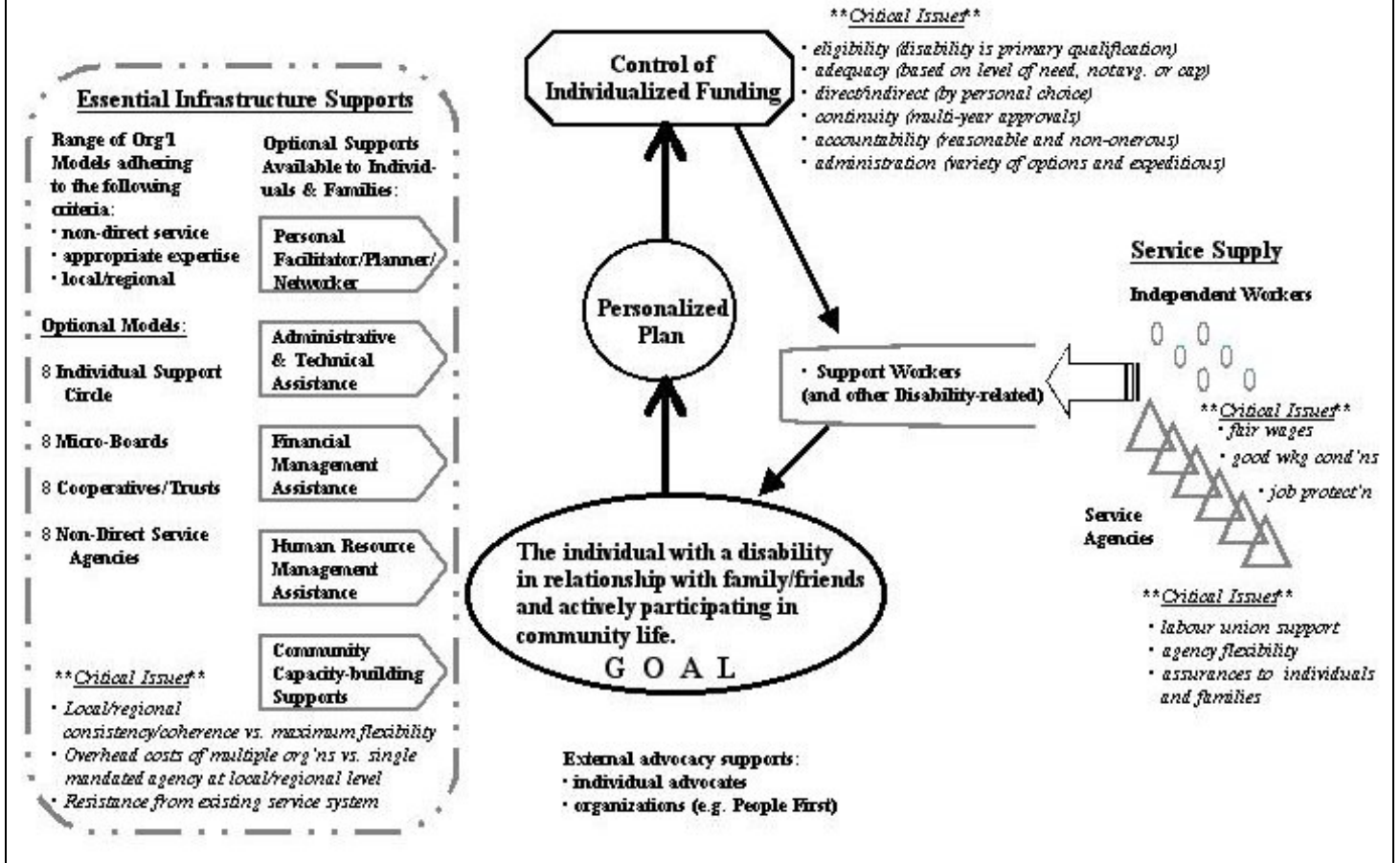
The principles and policy framework developed by the Round Table serve as a basis for creating significant and important change in the way disability supports are provided in Ontario. We recognize that implementing this policy framework will require some strategic thinking and planning about how to deliver such a policy throughout the province in an equitable manner. In the diagram on the following page, we illustrate the main implementation components that will need to be in place for the principles and policy framework to become viable. Implementation issues associated with each component of the policy framework are also identified. For each component, we also recommend implementation directions and strategies.

### **The Personalized Plan and Consumer Control**

The personalized plan is at the centre of our diagram. We believe the person and their network must develop the plan, and the person's plan must drive the individualized support and funding. To ensure that the individual

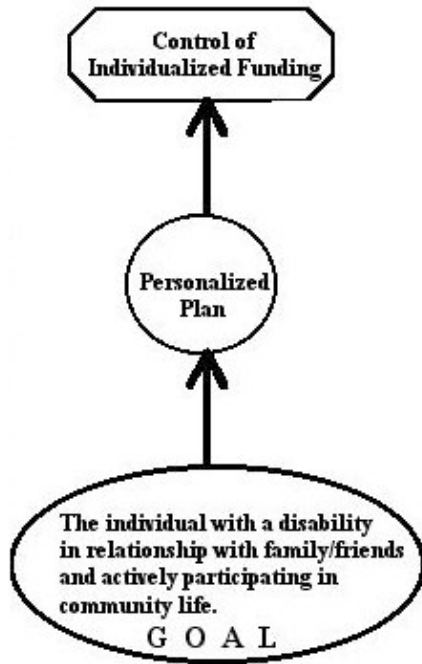


**Policy & Program Framework for Person-Directed, Disability-Related Supports**



and their network have control, planning support must be strongly value based. Facilitators, who are an essential infrastructure support, must be trained to nurture individual and family self-reliance, network building, and plan development. Many practical ideas are now available on the process of developing and implementing person-focused plans.<sup>ix</sup> Below we recommend

ways that implementation will have to address personalized plans and consumer control.



As our diagram illustrates, the personalized plan is driven by the goal of the person with a disability in relationship with family and friends and actively participating in community life. The values associated with this goal should be foremost in the implementation and in the training of people who will facilitate the planning process. An important part of the viability of direct

funding is the capacity of families, friends, and community to play an important role in the life of citizens with disabilities.

The implementation directions and strategies emphasize the importance of eliminating any possibility of “conflict of interest” of facilitators. Our research has strongly pointed to the value of unencumbered planning. In other words, facilitators should not be tied in any way to the

service system, but be free to plan and advocate with individuals and families.

**The Personalized Plan and Consumer Control:  
Implementation Directions and Strategies**

- The individual and their network must always have control of the individualized planning process.
- Suggested planning steps, processes, and resources must be available to individuals and their networks.
- Facilitators who support individuals in developing their personal plans should be trained to nurture the capacity of individuals and their networks to plan and participate in the life of the person.
- Facilitators and families should be educated to fully involve the person with a disability in all decision-making, even when this requires extensive supported decision-making.
- Funds should be available for those individuals who want to hire their own facilitator.
- Facilitators must not be attached to organizations that provide direct services to adults with disabilities.
- The role of the facilitator is to get to know the individual and their network very well, serve as a resource person for information and referral, and assist in the development and implementation of the plan.

## **Mechanism for Direct Funding: Control and Choice**

Once an individual and their network have a plan, they submit the plan to an allocation group. The preferred option would have the local Area offices of the government appoint an adjudication panel to make recommendations for funding. Other options presently in Ontario include a Community Priorities Panel (Windsor) or an Adjudication Advisory Group (Family Service Association, Toronto). If the community is going to make allocation decisions, the process needs to be separate from the infrastructure supports. The process should be clear and simple so that individuals and their networks can have as much control and choice as possible. Below we recommend ways that implementation will have to address direct consumer funding.

### **Mechanism for Direct Funding: Implementation Directions and Strategies**

- It is preferable for government to provide the direct funding, so that community structures can focus on planning and service delivery. Should this option not be possible, it is essential that allocation and funding decisions be separate from the infrastructure supports.
- Eligibility criteria for receiving direct funding should be based on physical and/or developmental disability, and the need for disability support. Individuals and their networks, in conjunction with local

facilitators, will determine the amount of informal and formal, paid support the person will require, and submit this with their plan.

- The application form for direct funding will be designed so that people's strengths and capacities, not just needs, are emphasized. People should also be asked what the person will accomplish (outcomes) as a result of the individualized disability supports.
- The application form for direct consumer funding for individuals, who cannot self-direct, will include the naming of a designate or representative, who will have the responsibility of making decisions about the person's supports. We strongly recommend that the person's network also be involved in this process, to reduce the vulnerability and dependence on one person. Also, it is expected that supported decision-making will insure that individuals who are unable to self-direct will be full participants in the decision-making process. Facilitators will play an important role in balancing possible differences in network member's interests and concerns. We see this as a creative enterprise based on a person-centred approach.
- Criteria for funding should be based on the Round Table principles, and reflect people's capacity to build networks and nurture community involvement. Direct funding is cost effective when it is utilized for a range of people, not just for people with the most obvious needs.
- To ensure continuity of support, allocations should be permanent, with monthly financial accountability, and more detailed review and reporting after each year, with funding adjusted accordingly.
- Although there should be no arbitrary caps with the direct funding, parameters and "benchmarks" will need to be set, related to a reasonable quality of life. For example, the range and maximums that the direct funding will pay for things like speech therapy, physiotherapy, and tutoring will be outlined.
- Individuals and families must be accountable for all expenditures they use for disability supports. Individuals and families should have the choice of receiving payment up front or after expenditures, with receipts being essential for both approaches.

Equity is a key principle related to the direct funding mechanism. Effective direct funding projects like the Western Australia Local Coordination serve a range of people with disabilities. Participants include people with developmental disabilities, individuals with physical disabilities, and needs ranging from mild and moderate to extensive. Equity insures that everyone has an equal chance of being chosen. As well, the range of people being served has been shown to increase the cost effectiveness of the program. For equity to be more of a reality in Ontario, new resources will be needed for a new direct funding program.

The Round Table recommends that there should be no arbitrary cap on disability support expenditures. The Ontario experience is that when there is a cap, such as \$55,000 for people returning from institutions, then everyone who applies tends to receive the maximum. The experience in Alberta and Western Australia is that without funding caps, there is a much wider range among the funding allocations, as people choose what they actually need. As noted above, there is a need for funding parameters or ‘benchmarks.’

## Essential Infrastructure Supports

In order to provide individualized disability supports, essential infrastructure supports must be provided for individuals and their families/networks. We have already identified the importance of the facilitator.



In addition, administrative and technical support assists individuals and families with the application for direct funding, including the areas of support to which the funding is applied. Below we recommend ways that implementation will have to address the essential infrastructure supports.

We are not recommending one approach for the development of the essential local infrastructures throughout the province. Each local area or region might have a

unique approach, but would be guided by the provincial principles and policy framework. There is diversity across the province that could be the starting point for building the infrastructure supports.

### **Essential Infrastructure Supports Implementation Directions and Strategies**

- The purpose of local infrastructure supports is to provide individuals, families, and their networks with several different support options, all designed to enhance their individualized disability supports.
- Several functions must be part of the infrastructure supports; personal planner, facilitator, broker support; administrative and technical support; financial management assistance; human resource management assistance; and community capacity building supports.
- The development of these supports should be local and regional, guided by provincial principles and policy framework.
- There must be criteria for any group or organization to be able to provide the infrastructure supports, including that the organization;
  - is clearly separate from the service delivery system,
  - has the technical and training capacity, and
  - has a philosophy and value base that is consistent with the principles.
- Should individuals and families choose to self-administer their individualized support dollars, they should be able to access financial management supports to assist them with this administration.
- Community capacity building supports enhance the community involvement of individuals with disabilities, and should be designed to build welcoming settings in communities.



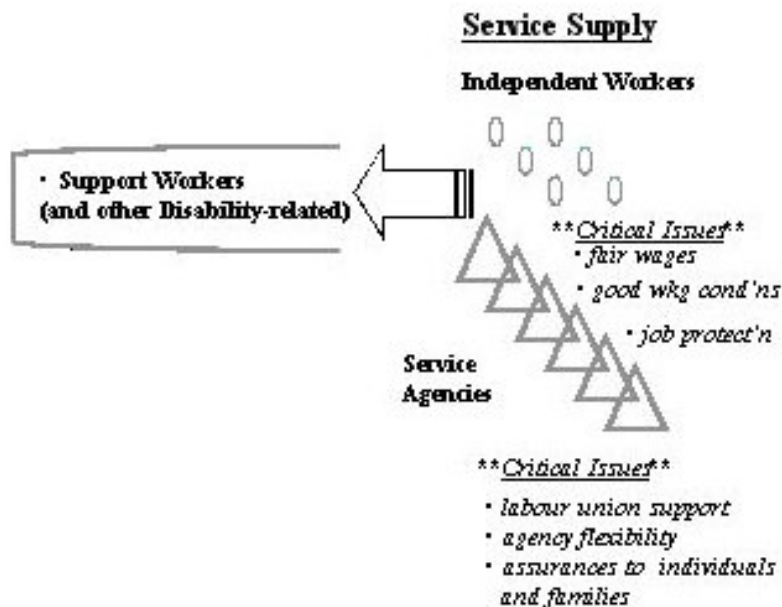
- Some communities already have separate non-service delivery organizations that provide facilitators for person-centred planning and direct funding. Organizations such as the Toronto Family Service Association (Individualized Quality of Life Project) and Windsor-Essex Brokerage for Personal Supports provide several infrastructure supports that are separate from the service system.
- Other communities might utilize different existing structures to build their infrastructure capacity. In a few areas of the province, for example, single point access agencies in developmental disabilities have many characteristics that could form the basis of an appropriate organization to house some of the infrastructure supports. Similarly, several Independent Living Centres across the province currently provide support to individuals who are eligible for the Direct Funding Project, and might be well positioned to provide some of the infrastructure supports for a new program that met the needs of people who cannot self-direct.

These are examples of how communities might address the essential infrastructure supports. Local communities would have the choice of what works best for them. What matters most is that a community understands all

the functions that are required, and then builds the structures to appropriately address the functions. If the infrastructure functions are to exist in more than one organization, there is merit to clustering the functions. For example, it would make sense that the person-directed planning function be associated with the building community capacity function. As plans evolve, and implementation gets underway, it will become apparent what parts of the community will need to be nurtured and developed.

## Supply of Workers: Fairness and Flexibility

In implementing an individualized disability support approach, it is essential to provide an adequate supply of support workers when individuals



want and need the support. Two types of workers should be available to provide support; independent support workers, who may be self-employed or who may work directly for the individual and family; and support workers who work for an agency, that can be employed by an individual and family. Research suggests that both types of approaches are needed in order to have an adequate supply of workers.<sup>x</sup> We also know that fair wages are critical to maintaining support workers in their positions.

Unions have sometimes expressed concerns with individualized funding, because they fear it will create an unorganized, low wage workforce. It needs to be recognized that this fear has some basis to it, and safeguards are required to insure that workers receive fair wages and opportunities for training and support. Although little research exists on the role of workers within direct funding programs, lessons from some projects suggest that workers find the context of individualized planning and support affirming and meaningful.<sup>xi</sup>

The key issues for workers are fair wages and security. Organizations in Toronto, Thunder Bay, and Windsor that have been moving in significant

ways toward individualized supports and funding, have been able to build safeguards into collective agreements. Such approaches honour the rights of individuals and their networks to choose how they want to receive their disability supports. At the same time, workers rights for fair wages and some security are also honoured. Although there is some tension between these requirements, finding common ground will be key to agencies that want to move to individualized approaches.

Below, we recommend ways that implementation will have to address the issues related to the supply of workers.

**Supply of Workers: Fairness and Flexibility  
Implementation Directions and Strategies**

- To insure that direct funding does not create a low wage sector, government needs to set guidelines for the payment of support workers, whether they are self-employed or work for an agency. There are examples in other jurisdictions where this approach works very well. These guidelines for fair wages can be built into any direct funding allocations.
- Recruiting and hiring support workers should be addressed with a multi-level approach. Individuals and families need to be provided with strategies to recruit and hire their own workers if that is their wish. Agreements with agencies that will provide workers also need to be developed. A list of the agencies that provide such workers should also be available to individuals and their networks.

- The lead infrastructure organization, or another assigned group, should provide extensive value based training for workers. Families should be encouraged to build “required training” into their contracts with their workers. The training should include values and principles outlined in this report, strategies for “working for” a person with a disability, ways to facilitate supported decision-making, and outcomes designed to enhance self-determination and community involvement.
- Organizations and unions that have been successful in completing collective agreements that allow workers to participate in direct funding programs, should share their lessons with others who are embarking on this journey.

## CONCLUSIONS: TIME FOR ACTION

The Ontario Round Table on Individualized Funding has three main recommendations:

- 1. That the Ontario government adopt the principles, policy framework, and implementation directions of the Round Table.*
- 2. That the Ontario government work closely with citizens and stakeholders throughout Ontario to implement the principles, policy framework, and implementation directions.*
- 3. That community organizations involved in providing disability supports work with other groups in their communities to implement the principles, policy framework, and implementation directions of the Round Table.*

The recommendations made in this report are congruent with social policy that ensures the best possible access to supports that respond to the basic needs of people with disabilities. The option of direct individualized funding enables individuals and families to take control of those aspects of daily life that are essential for self-sufficiency and dignity. In a society with traditions of equity and fairness, direct funding and individualized support

reinforce the long-standing recognition of the value of individual and collective responsibility for over-all well being.

Expanding the capacity of direct funding initiatives to reach more citizens with disabilities in Ontario requires the involvement of both the Ministry of Community and Social Services and the Ministry of Health and Long Term Care. *The vision, principles, and process of individualized disability supports is so compelling that we have concluded that new money and a new program should be put in place throughout the province.* New money would address the support needs of some of the thousands of citizens with disabilities who are waiting to receive funding for disability supports so that they can participate and live more fully in the community. This direct funding program would be both equitable and a very cost-effective way to address this issue. The new program would also ensure that existing programs such as the Direct Funding Project would remain intact for those people with physical disabilities who can self-direct. The new program would ensure equity by providing similar individualized disability supports for other citizens.

We submit our report in the knowledge that there remains much more to do in planning strategically the way in which this report can be implemented. As we reviewed project documents and evaluations for this work, we were constantly reminded of the importance of principles and policy in guiding action. Ideas should drive policy and individualized disability supports are a good idea. It is time to act on the idea.

We have suggested throughout this report that action must take many forms. The provincial government needs to take the lead on the policy framework and the expected standards for implementation. Regional offices of the government and local communities need to work together to ascertain how best to implement the principles, policy framework, and implementation standards within their localities. Disability self-help groups and family groups need to invest in further education to ensure that individuals and families are ready for this initiative. The Individualized Funding Coalition initiatives will also help educate and mobilize communities.

Finally, the new program must include ongoing research and evaluation. The focus of this research should be on outcomes and learning,



which will enable us to stay focused on the goal of enhancing self-determination and community involvement of all citizens with disabilities.

## ENDNOTES

- <sup>i</sup> A Review of Individualized Funding has recently been completed for the Ontario Federation of Cerebral Palsy. This review highlights several lessons related to principles, policy, implementation, and strategies for change.
- <sup>ii</sup> In 1998, the federal and provincial governments signed an agreement, entitled In Unison, which identifies citizenship and several other progressive directions for enhancing disability supports.
- <sup>iii</sup> Groups that have positions on this issue include: Ontario People First, Canadian Association of Independent Living Centres, and the Council of Canadians with Disabilities.
- <sup>iv</sup> For further insight into this issue of vulnerability and health, see John Lord and Peggy Hutchison, Living with a Disability in Canada: Toward Autonomy and Integration, Determinants of Health, Canada Health Forum. Ste.Foyes, Quebec: Editions MultiMondes.
- <sup>v</sup> These lessons are outlined in the Review of Individualized Funding.
- <sup>vi</sup> The values and principles set out by these projects shift control to the person and their family. Thus, the term “self-determination” is quite common in these initiatives. Many programs also emphasize community involvement and inclusion. The principles and values of other initiatives are outlined in the Review of Individualized Funding.
- <sup>vii</sup> We strongly support self-determination and community involvement, because together these two processes can lead to a “textured life.” Alison Pedlar and her colleagues coined the concept of a textured life, in an important Canadian study that showed that people’s quality of life is related to involved social networks as well as to control and participation of their disability supports. See Alison Pedlar, Larry Haworth, Peggy Hutchison, Peter Dunn, and Andrew Taylor (1999). A Textured Life: Empowerment and People with Developmental Disabilities. Waterloo: Wilfrid Laurier University Press.

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<sup>viii</sup> See Stephen Covey (1990). Principle-Centered Leadership. New York: Simon & Schuster.

<sup>ix</sup> See, for example, John O'Brien and Connie Lyle O'Brien (1998). A Little Book About Person Centered Planning. Toronto: Inclusion Press.

<sup>x</sup> In the 1993 Review of the Special Services at Home Program (Centre for Research and Education, Family Directed Support: Diversity, Hopes, Struggle, Dignity), it was found that areas of the province that did not have agencies with workers that families could hire contributed to families frustration.

<sup>xi</sup> See the Review of Individualized Funding; John Lord (1998). The NABORS Experience: Lessons in Community Building. Toronto: Green Dragon Press, and Alison Pedlar et al. (1999). A Textured Life: Empowerment and People with Developmental Disabilities. Waterloo: Wilfrid Laurier University Press.

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