Transformation and Disability Supports

The Role of Individualized Funding

A summary
presented to the
Ministry of Community and Social Services
by the
Individualized Funding Coalition for Ontario

This response would not be possible without the input from many citizens throughout Ontario.

First, the Individualized Funding Coalition for Ontario wishes to thank all its members who advocate for individualized supports and funding on behalf of the many individuals with disabilities and their families.

Second, the Coalition wishes to thank the Partner Organizations for their input and support throughout the years.

Third, the Coalition wishes to thank the more than 125 participants of the February 2004 "Workfest" who laboured diligently all weekend to identify the needs, visions, strategies, issues and barriers surrounding Individualized Funding. Documents produced from that labour are included in this submission.

Fourth, the Coalition wishes to thank all of the respondents to our call for input on this Preliminary Discussion Paper.

Fifth, the Coalition wishes to thank the Honourable Sandra Pupatello, Minister of Community and Social Services for recognizing the need for change to the way people with disabilities receive supports and services and to the Ministry for inviting the Coalition to respond to the Preliminary Discussion Paper.

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Supports for citizens with disabilities can be characterized in two ways;

- *Disability supports* refer to those supports and services that help a person deal with their impairments or disabilities. Disability supports are generally very practical and assist the person with personal care, access to the community, and assistance with daily life participation. For many people with disabilities, these supports need to be individualized and available on a regular basis. Disability supports could include, but not be limited to, attendant services, personal assistance, homemakers, technical aids, therapeutic services, co-ordination and facilitation, etc.

- *Income supports* refer to those supports that provide funds for living, and include employment supports, pension income schemes, etc.

This review will focus primarily on disability supports.

Toward a New Paradigm of
Disability and Community

During the last twenty years, support systems for citizens with disabilities have been undergoing significant changes. The traditional community service delivery system that was established in the 1960's and 1970's is firmly established throughout Canada. At the same time, there have been many alternatives proposed and a large number of innovative projects that demonstrate the principles outlined in *In Unison.* There is a growing body of literature and research that points to principles, processes, and strategies for shifting the paradigm in community support systems.

Let us begin with a summary of some of the features of the traditional service delivery system and the emerging paradigm.

The Traditional Service Delivery System

The *traditional service delivery system* for people with disabilities in Canada has many features that are typically seen across various types of disabilities;

- delivery of services is usually done through transfer payment agencies
- funds are available only to agencies and not directly to individuals
- many services are provided in congregate settings, rather than being individualized
- supports tend to be professionally driven, and citizens with disabilities play a minor role in planning and directing their supports
- the focus of many community services are rehabilitation oriented and institutional services play a major role in people's lives

- services are designed to "help" rather than being designed to build capacity of the person, their family and the community
- services are usually poorly co-ordinated, and duplication of services is common
- the focus of supports is generally on practical supports rather than on facilitation of social inclusion in community.

An Emerging Paradigm of Disability and Community

An *emerging paradigm of disability and community* reflects significant changes in the traditional service delivery system. Paradigms of disability and community have emerged in theory and practice in the last twenty years. They can be seen in a patchwork approach to innovation across the country. Research is beginning to reflect the new paradigm, and show very positive outcomes for people with disabilities. The features of the emerging paradigm are consistent with the principles articulated in *In Unison* (Nelson, Lord, and Ochocka, 2001; Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999; Individualized Funding Coalition, 2000; Roeher, 1991). Some of the features of the emerging paradigm of disability and community are:

- people with disabilities have control and choice in the way their disability supports are provided
- there is a focus on individualized planning, support, and funding, that are designed to facilitate natural, informal support (family and friends) and to build citizenship opportunities
- there is a focus on positive social roles that involve personal relationships, participation in the community, and opportunities to contribute. These domains are seen as critical to reducing the vulnerability of people with disabilities and safeguarding quality of life.

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- planning and support are emphasized to 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.

- funding is often dedicated to the 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; and people with disabilities live and work where they choose.

- planning for the individual tends to 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 disability supports.

With the exception of *In Unison*, there are only a few national or provincial policies that currently support the emerging paradigm. On the other hand, researchers and policy analysts have proposed various policy frameworks that fit with the emerging paradigm. A recent study of community mental health outlines a paradigm that emphasizes empowerment and participation, community integration and support, and access to valued resources and social justice (Nelson, Lord, and Ochocka, 2001). The Roeher Institute has proposed a framework that focuses on self-determination, democracy, and equality (Roeher Institute, 1996). A recent national study identified factors, including relationships and individualized support that facilitate a "textured life" for people with developmental disabilities (Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999; Pedlar, Hutchison, Arai, & Dunn, 2000).

The Individualized Funding Coalition of Ontario recently sponsored a Round Table on Individualized Funding that produced a policy framework for an individualized system of disability supports.

Across Canada, the patchwork approach to innovation has also produced several interesting and important evaluation reports that shed light on how to implement the emerging paradigm (Kendrick, 2001; Lord, 1998, 2000; Nelson, Lord, & Ochocka, 2001; Pedlar, et al., 1999; Roeher, 1997, 2000; Women's Research Centre, 1994). Many of these policy frameworks and innovative practices will be discussed further in the sections that follow.

Understanding the Context

This section will set the context by identifying some societal factors that are having an impact on service delivery. These factors include;

- an aging society
- determinants of health research
- first generation of parents committed to inclusion
- growing dissatisfaction with agency driven support systems and consumer demand for change
- re-discovery of the power of community

Aging Society

Canadian society has been aging during the last three decades and is expected to continue to do so over the next fifteen years. Statistics Canada (1998) data further confirms that disability increases with age. The disability rate is 5.2 percent in the 0-14 age group, 5.7 for those 15-34, 15.5 percent among those aged 35-64, and 45.5 percent of people over 65. Of people over 65, more than 75 percent have multiple disabilities.

These two factors, an aging society and the relationship of aging to disability, have enormous implications for community service systems. First, it is creating extensive demands for more appropriate services that address issues of aging. Service systems are responding slowly to the demand for more appropriate services. Research on aging and disability is growing, showing that more individualized and flexible approaches are needed.

Second, issues of our aging society are spawning creative approaches that help ensure the long-term security of individuals and families. One of the dilemmas that many families face is the "uncertainty" of what will happen to their adult children with disabilities when the parents die. PLAN (Plan Lifetime Advocacy Network) in British Columbia has developed a family based support system to assist families with these issues. Individuals are supported to develop their networks as the basis for long-term security, while families are supported to plan appropriately for their wills and estates. Al Etmanski has written the book *A Good Life* (2000) that outlines in detail the PLAN approach.

While the aging society will undoubtedly continue to stimulate innovations such as PLAN outside the service system, *the service system itself is being driven to be more flexible and individualized as more and more Canadians experience disability personally or within their families*.

Determinants of Health Research

Definitions of health are changing and this has created a new context for understanding disability supports. For decades health was considered "absence from illness." The Lalonde report in the 1960's re-framed health to encompass lifestyle factors. By the mid-1980's, it was clear that even a lifestyle approach to health was limited. The World Health organization has defined health as "the extent to which people have control over their lives" (World Health Organization, 1987). Determinates of health research has shown that health is a function of several factors, including income, social support, personal control, and participation (National Forum on Health, 1998).

The reality is that a large number of Canadian citizens with disabilities experience many of the indicators associated with poor health – powerlessness, unemployment, social isolation, and poverty. Determinates of health research creates a context to view disability in broader terms and to work toward changing conditions that can empower people to enhance their quality of life. *Ensuring that people have access to quality disability supports is increasingly seen as critical to addressing determinates of health* (Lord & Hutchison, 1998; Individualized Funding Coalition of Ontario, 2000). When people can access individualized and high quality disability supports, they have a base for participation and employment. Obviously, income and employment policies as well as housing

policies need to complement disability support policy, but one will not work without the others.

First Generation of Parents Committed to Inclusion

The focus of parents that have children with disabilities has changed dramatically during the last three decades. Parents who had children growing up in the 1950's and 1960's advocated for segregated schools and group homes. This work helped establish what we now call the "traditional" service system. Parents who now have young children with a disability have a different focus. They have grown up in times of rights, broader acceptance of disability, and a widespread focus on inclusion and integration. This first generation of parents committed to inclusion is having an impact on the evolution of service systems.

More and more parents are demanding home supports, control over disability supports, and genuine options for their sons and daughters when they reach adulthood. In the 1993 evaluation of the Special Services at Home Program in Ontario, the most important feature of the program for families was "control" (Lord, McGeown, & Ochocka, 1993). The focus of families on having control over supports as well as inclusion in community life is pushing service systems to create more responsive disability supports.

It is clear from the work completed by the Individualized Funding Coalition that many, many families in Ontario are ready for individualized funding. This is the result of many workshops that families have attended across the province as well as growing dissatisfaction with agency driven services, which is discussed below.

Dissatisfaction with Agency Driven Support Systems
and Consumer Demands For Change

Most community service systems have been designed in order that community agencies receive block funding and then provide support to individuals or groups. Access rules are generally determined by the agency, and family and consumer participation is limited. People with disabilities and family members have become increasingly dissatisfied with these agency driven support systems (Felce, Lowe, Perry, Jones, Baxter, & Bowley, 1999; Fulcher, 1999; King, 2000; Marquis, & Jackson, 2000).

In the last two decades, there have been several outlets for people with disabilities to express their views and critique current practice. Several Canadian organizations have been instrumental in framing alternative approaches to providing disability supports. At the heart of these alternatives is the critique of professionalization and dissatisfaction with limited options. If the group home agency is the only option, is this really a choice? If the apartment complex with attendant care is the only option, is it really a choice? *Consumer demands are framed in many ways, but what they have in common is a strong desire for choice and control.*

Among the national groups that have articulated alternative approaches to providing disability supports, the work of the Canadian Association of Independent Living Centres illustrates the emerging paradigm (Hutchison, Pedlar, Dunn, Lord, & Arai, 2000). The Canadian Association has challenged the rehabilitation paradigm, which is seen as being professionally controlled, focused on deficits, and treating people as dependent clients (Canadian Association for Independent Living Centres, 1991; Schwartz, 1992). Independent living was introduced as an alternative to traditional services (De Jong, 1979). The

independent living paradigm emphasizes that the problem lies in the environment, in segregation, discrimination and in a dependency upon professionals (Carpenter, 1991; Crewe & Zola, 1984). In terms of disability supports, the main principles of the Canadian Association of Independent Living Centres include; consumers define their own needs, consumers direct the supports they require, and consumers have choices and knowledge that empower them to participate fully in community life (Hutchison & Pedlar, 1999; Hutchison, Pedlar, Lord, Dunn, McGeown, Taylor, & Vanditelli, 1997).

Other consumer and family advocacy groups, such as the Canadian Association for Community Living, the Canadian Mental Health Association, and the Council of Canadians with Disabilities, have emphasized similar elements. *Frameworks and alternatives emerging from consumer and family organizations are consistent with* **In Unison** *and create a positive context and demand for change.*

Re-Discovery of the Power of Community

In the last two decades, the power of community has been re-discovered. From the 1950's through the 1970's, most efforts related to disability supports focused on improving formal service systems. The dissatisfaction with agency driven approaches described earlier was accompanied in the 1980's and 1990's by a growing interest in community. People with disabilities were more and more viewed as citizens with the same rights as others. Disability movements were beginning to stress the importance of inclusion and full participation.

The re-discovery of the power of community has had a significant impact on our view of disability supports. Person-centred planning and network building are just two of the ways community is emphasized in many new disability support

approaches. Person-centred planning involves gathering people around a person with a disability to assist the person in developing a plan for their life (O'Brien and Lyle O'Brien, 1998). Network building addresses the isolation that many people experience and intentionally invites people into the life of the person. Support circles, support clusters and other similar approaches are becoming widely utilized as concrete approaches for facilitating person-centred planning and network building (Lord and Hutchison, 1998).

Community and citizenship become key elements in a service system designed to reflect **In Unison**. In practice, this means disability supports must become more individualized and tailored to the needs and gifts of individual citizens. It means that informal supports are incorporated alongside formal, paid supports. Finally, it means that citizens with disabilities will have genuine self-determined personal support options that enable full participation in community life.

The Individualized Funding Coalition believes that citizenship approaches by their very nature demand that supports be individualized. This means, as reflected in the *Round Table Report of the Coalition*, that infrastructure supports, such as independent planning and facilitation, must be available along with individualized funding, in every community of Ontario.

Toward Individualized Supports and Funding

Consumer demands and the limits of agency driven systems have led to increased focus on individualized support and funding. At the moment, there is a patchwork of individualized approaches throughout Canada. Research and evaluation reports point to very positive outcomes for services and systems that are individualized. One focus of particular interest is the notion that individualized approaches builds capacity of individuals, families, and communities. Emerging policy frameworks also raise questions about the best policy alternatives. In this section, we shall explore each of these ideas.

Some History of the Move to
Individualize Support and Funding

In early 1980's, there were parallel initiatives within various disability sectors that pointed to the need to make disability supports more personalized. The independent living movement, developed in the 1960's in Berkeley, California, spearheaded the idea of personal support services and attendant care. Throughout the western world, people with physical disabilities began to advocate for attendant services that were directed by the person requiring support.

During the same time period, the community living movement in Canada was a primary advocate for deinstitutionalization. During the de-institutionalization of the Woodlands Institution in British Columbia, the Woodlands Parent Group got the government to agree that a brokerage system would make sense. Essentially, brokerage services are separate from other direct services, and enable the individual consumer to pick and choose from an array of

available services and community opportunities. This was possibly the first individualized funding approach in North America.

All the early movements for individualized support and funding based their belief for change on common new directions. One was that *housing and support should be de-linked, no longer dependent one upon the other*. This was a radical idea at the time, because it meant that disability supports could be accessed wherever you lived. By the mid-1980's, alternatives to congregate living were in full bloom. Supported independent living projects, individual apartments with support, and more flexible support worker schedules were emerging. In most cases, however, these early ideas related to individualized support were within the structure of community agencies, and did not relate to individualized funding. *People were beginning to experience options and they wanted more choice and control!*

As more and more individuals and families experienced individualized support, the desire for more control and choice became a rallying call for improved disability supports. In the mid-1980's, the province of Alberta developed the most comprehensive approach to individualized funding, and by 1990, it had become the official way for service delivery in that province. Financed and administered under the Social Services Act and the Persons with Developmental Disabilities Act, there are two separate programs, one for people with developmental disabilities, and the other for adults with physical disabilities. *Although there were significant delivery issues with Alberta's approach to individualized support and funding, the widespread use of these approaches created an important context for learning*.

During the same time period, the province of Ontario was developing the Special Services at Home Program (SSAH). Under SSAH, families with children

who have physical or developmental disabilities can receive individualized funds for respite, family support, community integration, or individualized supports. SSAH created an important history of learning around direct funding in Ontario. The 1993 SSAH evaluation showed that families appreciated having more control over the disability supports in their lives (Lord, McGeown, & Ochocka, 1993). Since 1995, Family Alliance Ontario has stressed that SSAH is a very effective program and has asked the Ontario government to fund "consumer-directed individualized funding" more widely. In recent years, other provinces have begun to implement individualized family support programs.

Also during the mid-1980's, groups of citizens with physical disabilities were advocating for direct funding for attendant services. Up to that point, most attendant service projects in Canada were linked with housing, which meant that people had to live in a certain setting in order to access attendant services. The most successful group in Canada was the Ontario Attendant Care Action Coalition, which advocated for a direct funding pilot project. In addition to advocacy, a major review of support services (Lord, Hutchison, & Farlow, 1988) provided impetus for the province of Ontario to initiate the Direct Funding Project as part of their reform to long term care in 1993 (Roeher, 1997). Since that time, several other provinces have started developing direct funding for attendant service projects.

Elements of a Personal Support System that is Individualized

All of the initiatives outlined above have created a context for learning about how to implement more individualized disability supports for people with disabilities. By the mid-1990's, there were numerous projects and pilot initiatives across North America and Europe and a growing movement committed to individualized approaches. As examples, the Ontario Association for Community

Living adopted a policy in favour of individualized funding by the early 1990's. The Canadian Council of Canadians with Disabilities has been a strong advocate of direct funding for attendant services. In the United States, the National Program on Self-Determination, funded by the Robert Woods Johnson Foundation, has sponsored self-determination and individualized funding projects in nineteen states (National Self-Determination Program Office, 2000), and in the year 2000, collaborated with other groups to sponsor an international conference attended by more than 1600 people in Seattle. And in 1996, Great Britain adopted a Direct Payments program that is linked to local authorities who provide infrastructure supports to individuals and families.

The Individualized Funding Coalition for Ontario has developed a number of important ideas and resources related to individualized support and funding. The Coalition's belief in the value of individualized funding sets the tone for these ideas.

> The Individualized Funding Coalition 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 access to and control over the funds allocated to his/her supports.

In the fall of 1998, the Coalition sponsored a two-day Symposium that provided a framework for change. In the Symposium Report, entitled *Individualized Funding: A New Vision*, the Coalition identifies five "building blocks" that are necessary for successful individualized outcomes:

- person-centered planning
- personal support relationships
- individualization of funds

- management supports
- community development (Individualized Funding Coalition, 1999).

These elements for creating an individualized system of disability supports are consistent with the findings of the national self-determination projects in the USA. The *Self-Determination Projects* are based on four guiding values and principles.

- freedom: the ability to plan a life with supports rather than purchase a program
- authority: the ability to control a certain sum of dollars to purchase supports
- support: through the use of resources, arranging formal and informal supports to live within the community
- responsibility: accepting a role within the community through competitive employment, organizational affiliations, and general caring for others within the community; and accountability for spending public dollars in life-enhancing ways.

Self-determination projects have found that increasing consumer choice must be accompanied by building community capacity to provide personal supports in non-traditional ways (New Hampshire Self-Determination Project (n.d.; Michigan Department of Community Health, 1999). At the same time, efforts must be made to shift the organizations that provide services.

This three pronged approach (expand consumer control and choice, build community capacity, and shift traditional services) has proved to be a challenge, but essential as part of the process of the transformation in many jurisdictions.

In the Canadian context, Torjman (2000) argues that individualized funding and consumer choice is a critical part of implementing *In Unison*, but that resources must also be directed at building the supply of personal disability supports.

The Ontario Round Table on Individualized Funding (2000) places person-directed planning and network building at the heart of a reformed system. They envision individuals and families coming together with the assistance of a facilitator, expanding their network, and then developing a plan for personal supports. This plan would go to government or independent body that would provide individualized funding. People could then use their money to create supports or buy existing ones. Infrastructure supports for families and individuals would be available at all stages of the process, including a supply of workers and personal support services.

Direct individualized funding of disability supports is viewed by many as a mechanism for ensuring that the paradigm shift toward disability and community is grounded in genuine options and increased control for individuals and families. In many ways, individualized support and direct funding is consistent with the world-wide trend toward increased democracy, self-determination, and community involvement. In the last decade, we have learned a great deal about the elements of a system that must be in place to provide individualized support and funding. In the next two sections, we look at research that points to the specific ways that these elements can best be organized and delivered.

Examples of Initiatives that Focus on
Individualized Support and Funding

In the last decade, numerous jurisdictions have initiated projects that have focused on individualizing personal supports and funding. The types of initiatives with selected examples are outlined in the following chart.

<ins>Initiatives</ins>	<ins>Examples</ins>
Provincial or state government initiative	• Alberta – two programs through two separate departments. • Manitoba – In the Company of Friends, project designed to build networks and provide individualized funding for people returning from institutions. • Ontario – family support program for children with developmental and physical disabilities (SSAH) • Ontario – Direct Funding Project for adults with physical disabilities who can self-direct. • Western Australia – Local Area Co-ordination and Direct Funding for all citizens with disabilities. • British Columbia is implementing 17 planning centres throughout BC along with direct funding

Community-wide or province-wide non-government initiatives for families and networks.	• British Columbia - Micro-Boards for adults with developmental disabilities, • Ontario - Windsor-Essex Brokerage for Personal Supports, part of system reform for the region. • 19 states in the USA – Self-Determination Projects
Independent projects	• Ontario - Toronto Options Project (originally the Quality of Life Project) provides facilitation and individualized funding. • Manitoba – Self-Managed Brokerage Project for attendant supports, through the Independent Living Centre. • Some Foundations Projects (Sarnia, K-W, Hamilton, others)
Service organization re-design	• Ontario – Community Living St. Marys and Area creating two departments, one that focuses on person-centred planning, network building, and community development, the other on direct service.

**Summary of Research Evaluations
on Programs and Projects that Provide
Individualized Support and Funding**

A recently completed review examined ten programs that utilize individualized support and funding. Each of the programs had research evaluations completed on their process and outcomes. Lord (2000) and his colleagues identified several lessons from this research.

1. Language and practice related to individualized disability supports is inclusive and citizenship oriented.

2. Clear values and principles are a critical guide for programs and projects that are focused on individualized disability supports.

3. A policy framework for individualized disability supports provides coherence and equity.

4. There are pros and cons to attaching direct funding projects to service reform efforts.

5. Infrastructure supports for individuals and families are separate from the service delivery system, thereby providing opportunities for people to plan and have genuine choice.

6. The role of a facilitator/broker is a main feature of successful projects.

7. A direct funding mechanism is separate from infrastructures and there is a well understood approach to accountability.

8. "Learning as you go": it is important to pay attention to process.

9. Many positive outcomes can be attributed to programs and projects that focus on facilitation, individualized support, and direct funding.

For a further analysis of these 9 attributes, see More Choice and Control for People with Disabilities, published by the Ontario Federation of Cerebral Palsy (2000)

The Ontario Round Table on Individualized Funding (2000) reviewed existing projects and programs that deliver individualized disability supports. The Round Table indicates that there should be five major components to a policy framework.

- <u>principles</u> to guide programs and individual processes, such as equity and portability
- <u>infrastructure supports</u> for individuals and families, including person-directed planning supports, network building supports, and administrative supports
- <u>a mechanism for direct funding</u>
- <u>a well understood, simple approach to accountability</u>
- <u>a mechanism for individuals to transition</u> to this approach from traditional supports and services
  (Ontario Round Table Report on Individualized Funding, 2000)

In conclusion, *a policy framework is important for building sustaining approaches to individualized disability supports*. Few initiatives that were studied have coherence among policy, principles, and practice. Exceptions would include the Ontario Direct Funding Project and Western Australia Local Co-ordination, where 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 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.

Our Recommendations

Based on its previous work, the Individualized Funding Coalition for Ontario is making the following recommendations to the MCSS transformation process:

1.   **Transformation should include the development of a new initiative that enhances choice and control for people with disabilities and their families, including more options for individualizing disability supports.**

2.   **The Round Table Report produced by the Coalition in the year 2000 should serve as the foundational guide for the development of this new initiative, with its principles and guidelines for direct funding and infrastructure development.**

3.   **Local infrastructures and direct funding must be part of this new initiative, including independent planning and facilitation.**

4.   **This new initiative should be embedded in legislation that ensures local, independent planners separate from service provision. An adjudication process for direct funding, including transparent appeal mechanisms.**

5.	**To insure developmental success, this new initiative must be developed by MCSS in collaboration with experts in individualized approaches *and* with the Coalition, which has close relationships with several on-the-ground successful projects that are individualized.**

6.	**To ensure developmental success, MCSS and its collaborators should consider phasing in such a new initiative over three years. There are several possible starting points for phase I implementation, including 1.) creating options for SSAH and Foundations graduates who have already experienced individualized supports, and 2.) creating individualized funding for families who are supporting individuals with complex needs (this latter area is especially critical since many families draw their support from at least two ministries – MCSS and Health – and individualized funding would allow for a seamless, co-ordinated approach to funding and support).**

7. **Where to place the local infrastructure supports in communities will be a huge issue for the Ministry, but they will need to insure that any such supports are independent of service provision. Given the bureaucratic nature of the access centres, it is unlikely that infrastructure supports could be placed there either. Finding truly community based existing organizations, and twinning that with local steering committees and strong provincial leadership will help insure that independence is maintained.**

8. **It is recommended that an expert panel of innovative service providers, researchers, self-advocates, and family members study systems that have created spending frameworks for individualized funding and make recommendations to MCSS.**

9. **To fund a new Individualized Funding Initiative MCSS must be strategic in its analysis of funding mechanisms. Strategies include carrying out a savings audit on existing access centers and transfer payment agencies, re-framing the current residential services spending approach, and ways to provide cost effective incentives for innovation.**

Transformation and Disability Supports

A summary of responses received from members of the Individualized Funding Coalition for Ontario and participants at the Coalition's most recent event "Workfest"

Individual Summaries

> A total of 22 submissions were received. Two of those submissions
> have been submitted to the Ministry directly. While the contents of the
> submissions have been summarized; the actual submissions are not
> attached

The Individualized Funding Coalition for Ontario distributed the "Transforming Services in Ontario for People who have a Developmental Disability Preliminary Discussion Paper, October 2004" to all of its members. The document was also circulated to the participants of 'Workfest' which was a very successful weekend of intense work identifying needs, visions, strategies and barriers to Individualized Funding in Ontario.

Being a provincial wide volunteer organization, it was extremely difficult for everyone to come together to develop a response to this discussion paper. We therefore relied on written submissions from members from the groups previously identified. Submissions were prepared by individuals with disabilities; families of individuals with disabilities; service providers; advocates and family networks. There was also a core group of members of the Coalition who prepared a summary of Individualized Funding. These submissions are attached to this summary of responses.

The overwhelming message received from the submissions to this discussion paper is that the new generation of family who have chosen to keep their loved ones at home and fully included in society will not accept segregation as the next step. These families strongly desire **CITIZENSHIP AND INDIVIDUALIZED SUPPORTS/FUNDING.** We need progress toward this goal. However, the current system is unable to provide the continuation of true citizenship for these individuals and their families. Therefore, the Ministry of Community and Social Services must develop policies, which continue to empower individuals with disabilities and their families, rather than empowering agencies to take control of the lives of individuals who have become accepted and contributing members of their community.

First and foremost, the submissions stress that individuals with disabilities (be they physical or intellectual or both) are people first and must be recognized as valued, contributing members of society. As citizens, they must be afforded the same rights as everyone else. However, because of the nature of their disabilities, income supports are often necessary. As well, disability supports are required for individuals to fully access their community and to take their rightful place in society.

Many submissions emphasized that the current level of the Ontario Disability Supports Program does not enable individuals to live above the poverty line nor does it take into consideration the additional expenses associated with having one or more disabilities. The traditional system of disability supports imprisons individuals in segregated day supports, group homes and institutions, preventing individuals from effectively participating in and contributing to society.

The current developmental services delivery mechanism of funding transfer payment agencies to provide services designed to protect the individual with a disability from society is limited as a mechanism for inclusion. Several submissions noted the limitation of agency driven approaches as the only way to meet the needs of individuals. Agency funding does assist some individuals, but it fails to meet the needs of a vast number of people with disabilities. In addition, as long as funding is attached to programs, not individuals, segregation will continue. Segregation does not allow for true participation in the community. Segregation does not allow for self determination as the individual's life is reliant on the group of people they have been linked to within the program. Segregation severely restricts an individual's ability to learn life's lessons because they have no opportunity to make choices which affect their life. Without the opportunity to make choices and learn from those choices, there can be no growth. Without learning there is no growth, without growth there is no progress. Therefore a life without inclusion is a stagnant life.

In the following section, we highlight the main themes that come from our submissions. These themes are organized under each of the discussion paper's questions.

1. **What should be the roles and responsibilities of different parts of society in supporting individuals who have a developmental disability?**

EVERY MEMBER OF SOCIETY HAS A RESPONSIBILITY TO ACCEPT EVERY INDIVIDUAL REGARDLESS OF ANY DIFFERENCES. EVERY INDIVIDUAL HAS A RIGHT TO BE ACCEPTED. SOCIETY NEEDS TO VALUE ALL CITIZENS BY RESPECTING THE GIFTS AND STRENGTHS OF ALL PERSONS. PARTICIPATION IS THE VEHICLE FOR THE EXPRESSION OF CITIZENSHIP. EVERY INDIVIDUAL HAS THE ABILITY TO MAKE DECISIONS AFFECTING THEIR LIVES; THEY MAY JUST DO IT DIFFERENTLY AND MAY NEED SUPPORT TO DO SO. THEREFORE, EVERY INDIVIDUAL HAS THE RIGHT TO DECIDE HOW THEY WISH TO LIVE THEIR LIFE. ACCORDINGLY THE MOST FUNDAMENTAL PRINCIPLE MUST BE:

<div align="center" style="color:red">

NOTHING ABOUT ME WITHOUT ME!

</div>

<div align="center">

THIS THEME IS SUPPORTED BY THE FOLLOWING COMMENTS FROM OUR RESPONDENTS

</div>

Individual
- has a right to income & disability supports according to needs
- has a right to self determination, respect for human worth and dignity
- has a right to quality of life
- has a right to be provided with accurate information to enable them to make informed decisions and be given the opportunity to do so
- has a right to be provided with accurate information regarding their disability
- has a right to expect the same rights as other members of society
- has a responsibility to identify needs truthfully, honestly, and responsibly
- has a right and responsibility to insist that others accept the fundamental principle as identified above
- has a right and responsibility to take their rightful place in society

- has a right to anticipate the same levels of informal, natural support as anyone else and should be expected to provide the same to others
- has a right to expect to be treated with dignity and respect
- should be an active participant in their community doing meaningful and productive things, the same as anyone else according to their unique lifestyle and system of support
- be responsible to participate in personal planning, identifying strengths, needs, interests, dreams, anticipated outcomes, and financial supports required which specifically reflect individual circumstance
- has a right to have stability in their lives
- has a right to exercise their rights as citizens, and along with these rights comes the responsibility to fulfill their citizenship duty
- has a right to entitlement and equity in funding for a broad range of options best suiting their individual needs and lifestyle choice
- has a right to disability supports that are adequate, appropriate, and accessible and of their choice
- has a right to be recognized as a person, funded as an individual not simply as part of a group
- has the right to be a stakeholder in decisions affecting his/her life i.e. choice in type of support and/or workers

Family / Support Network

Responsibilities:
- to identify needs truthfully, honestly, and responsibly
- to assist the individual to determine their own life
- to help ensure that the dreams of the individual are center
- to respect the wishes of the individual
- to recognize the need to let go, accepting the natural progression of life
- to assist the individual to advocate for themselves
- to advocate solely in the best interest of the individual when necessary to advocate on their behalf
- to assist in the development of a circle of friends for the individual
- to provide guidance, love, emotional support
- to be accountable to the family member with the disability; ensuring funding is spent wisely, in the best interest of the individual, promoting community inclusion and as independent a lifestyle as is possible

Rights:
- to control adequate funding
- not to be intimidated by the 'experts' as they truly are the experts when it comes to their loved ones
- not to be subjected to the pressures of service providers wanting to keep status quo (segregated, congregated programs & services) that detracts from true citizenship, value, respect and from being seen as individuals
- to a fair and equitable process for funding and portability of funding
- to be equal stakeholders in the entire decision making process including policy discussions and decisions which affect their lives and the lives of their loved one

Government

Rights
- to expect an honest, truthful and responsible identification of needs from the individual / family/ support network
- to expect an honest, truthful and responsible accounting of any funding directed to the individual/family/support network

Responsibility
- to provide equitable and secure funding
- to ensure an acceptable level of disability income supports which take into consideration the unique needs of the individual and family as well as the increased costs of being disabled (present level of ODSP too low)
- to legislate disability supports (SSAH, I.F.)
  - having NO support entitlement is tantamount to a death sentence (an adult without care cannot survive; lack of such care leads to death; without funding they cannot obtain necessary care)
- develop legislation for social reform
  - establishing rights of disabled
  - establishing formal appeals mechanism
  - mandating that families are included in policy discussions & decisions
- to continue providing supports to facilitate full participation in society as has been the norm for children within the education system

- essential that individualized funding be developed to provide financial supports for full participation in community (day care, education, employment, transition periods, affordable housing, transportation, quality medical care, infrastructure for innovative delivery of supports)
    - establish independent facilitators / planners networks
    - establish citizen's advocacy networks
    - establish individual / family networks
    - making individualized funding available to all who want it
    - enabling individuals/families/support networks to self administer funding
    - establish better partnerships with other sectors of society
    - learn to trust individuals/families/support networks
    - including individuals/families/support networks in all aspects of policy discussions and decisions as they have to live with the decisions
    - recognize that they are supporting 'people' not 'things'
    - recognize that this is the 'our life'
    - recognize that needs are unique and ever changing
    - recognize individuals/families/support networks are the experts on the needs of the individual
    - look to other jurisdictions that are successfully making individualized funding work
    - look to other jurisdictions to answer questions like how best to determine adequate funding

- to be accountable to the individual
- to recognize the needs not just of the individual but of the family supporting that individual
- ensure seamless supports
- establish a 'one stop shopping' community resource to facilitate access to various supports
- ensure realistic wages for workers which includes benefits etc to enable hiring of trained, experienced, educated, dedicated support workers, thus reducing the high turn over rate
- fund supports not programs; allocating funds directly for an individual rather than an agency's program
- develop policies allowing for flexible, portable funding within the traditional supports model
- streamline service delivery to enable more direct service dollars
- mandate team meetings as part of I.E.P. to ensure that transition plans are meeting needs of individual, not just generalized plans
- ensure accountability on the part of the service providers and individuals/families/support networks

- ensure that large amounts of money are not spent on meetings with management of agencies struggling with issues centered around protecting their turf
- provide financial support to train appropriate service providers to provide inclusive supports
- provide financial support for further education
- ensure that appropriate skills are being taught to those who will be providing supports
- ensure that information available at colleges & universities is accurate and up to date
- educate society on the nature of disability to dispel myths because it is mostly ignorance not unwillingness that create barriers
- provide incentives and support to community entities willing to integrate individuals with disabilities
- to review agencies resistant to changing trends denying individual true rights as citizens

- develop policies that are
    - clear, fair and equitable
    - reflective of the times
    - enabling individuals/families/support networks to have access to funding
        - person centered
        - person directed
        - person & family controlled
        - flexible
        - portable
    - consistently applied to avoid discrimination
    - inclusive of all disabled individuals

Service Providers

- school boards need to connect individuals/families/support networks with service agencies, support groups, employment opportunities
- focus funding on inclusive activities and partnerships to increase community awareness and participation
- listen to the individuals, their families/support circles and respond to their needs in a flexible and creative way
- develop service contracts that are truly individualized according to needs, it is not enough to just change a few things
- be accountable to individuals and government
- recognize that their services may one day no longer be necessary
- properly trained to provide services and care according to needs
- recognize that they are working with community not for bureaucracy
- develop knowledge of services and opportunities available
- ensure policies, rules & regulations are not contrary to citizenship rights of individuals to have true choice
- free up dollars from restrictive formal programs/services which deny true choice
- service providers must 'unbundle' existing dollars and new monies should not be used to promote old ways as these prevent true choice, individuality and opportunity to be true citizens
- remember that they are serving 'people' not 'things'
- recognize that this is 'our life'
- recognize individual / families/networks as true stakeholders/partners not prisoners in a system
- recognize that their services/supports are not the only options
- give up 'control' of individual

Other Members
- acceptance of the diversity of the entire population
- remove all barriers, attitudinal and physical
- seek knowledge and skills to interact with all members of society
- provide supports needed for full participation
- welcome all people
- encourage involvement & participation
- be open to change
- be accessible
- be supportive
- request assistance when needed from individuals/families/support networks as well as service providers and government

NOTE: being part of community from birth, individuals are accepted and viewed as valuable contributing members of society. If individuals/families/support networks, government and service providers all work together modeling citizenship, then community will follow.

2.   What strategies and resources would help individuals receive seamless supports throughout their lives, including points of transition?

THE KEY TO PROVIDING SEAMLESS SUPPORTS LIES IN THE BEGINNING OF PLANNING WHEN A DISABILITY IS FIRST IDENTIFIED AND CONTINUING THAT PLANNING THROUGHOUT THE INDIVIDUAL'S LIFETIME.   THIS NECESSITATES ACCESS TO UNENCUMBERED PLANNERS / FACILITATORS TO ENCOURAGE THE INDIVIDUALS / FAMILIES / SUPPORT NETWORKS TO DREAM WITHOUT PREVIOUSLY CONSTRUCTED BARRIERS HINDERING THEM.   INDEPENDENT PLANNING MUST BE SEPARATE FROM SERVICE PROVISION.

THIS THEME IS SUPPORTED BY THE FOLLOWING COMMENTS FROM OUR RESPONDENTS

- inclusion approach which begins in education system must continue into post secondary education and employment
- consistency / continuity requires a cross jurisdictional approach involving cooperation & reform of Citizenship and Immigration, Children and Youth Services, Education, Ministry of Community and Social Services and Health as well as many others
- individualized funding that is flexible and portable to address changing needs
- personal planning key to full participation
    - access to regionally knowledgeable independent planners
    - planners/advocates to help attain necessary resources/services as it always seems to be a fight
    - facilitators will get to know individuals as they grow and therefore will have deep connection with the family/support circle and the community
    - allowing citizens to choose their life plan
    - periodic reviews of the life plan
    - designing supports to meet needs

- facilitators for change, hired to educate & assist Ministries to better understand the rights, needs, options
- single access point of entry for services that will track **all** needs in community not just accommodation to fully identify the needs of the community
- citizen's advocacy network to assist those who cannot advocate effectively
- develop family networking opportunities, to help families share ideas, successes etc
- involve school boards
- eliminate the need to apply yearly for SSAH funding
- remove restrictions on use of funding
- remove SSAH cap of $10,000
- adequate legislated resources to alleviate the uncertainty of future funding due to changes in governments; bureaucrats
- more dollars are necessary to improve existing supports and develop new individualized funding model
- use of brokerage models
- one caseworker per individual
- devising a 5 year plan for individuals and families
- independent living/housing options
- use of support circles to assist in planning, accessing services, advocating
- proper identification of needs
- proper supports from day one
- educate families and society
- provide families with funding security & assistance with advocacy at all levels (preschool, school, community) as necessary
- needs to be someone to ensure continuity otherwise services/ supports become disjointed increasing possibility of 'falling through the cracks"
- parents/support networks are driving force behind equity and change
- start community networks (circle of friends)
- teach young community to be accepting and as they age it will become the norm
- employment possibilities beginning in high school; allowing for different experiences, making use of job coach if required
- remember TRANSITION is not an event—it is an evolution and done properly an individual's life will truly be seamless

3. What supports and services that are currently available work well and should be built on for the future?

TO ENSURE FULL CITIZENSHIP AND IN ORDER TO CONTINUE AND IMPROVE SUPPORTS AND SERVICES, ALL MONEY FOR DIRECT SERVICES MUST BE ANNUALIZED, PORTABLE, FLEXIBLE, AND INDIVIDUALIZED

THIS THEME IS SUPPORTED BY THE FOLLOWING COMMENTS FROM OUR RESPONDENTS

1. **INDIVIDUALIZED FUNDING (I.F.) *IS* THE VEHICLE FOR TRUE CITIZENSHIP AND TRUE CHANGE**

   - proven to be successful; has improved quality of life of those individuals already able to access I.F.
   - cost effective
   - should be option of first choice or the norm, available to every individual/family/network
   - independent planning / facilitation enables self-determination, and future planning; identifies strengths & abilities, recognizes dreams and goals as well as needs, and identifies required supports
   - easily accessible from one funding source to meet all the needs
   - available across jurisdictions beginning with Children and Youth Services; Education; Community & Social Services, Health, and other ministries as they become involved in the individual's life

2. **INCLUSIVE EDUCATION (when truly inclusive) IS WORKING BUT NEEDS IMPROVEMENT**

   - proven to be successful
   - enables individuals to be true citizens as they are accepted members of society
   - has improved quality of life of those individuals
   - builds community in schools and in social settings

- allows for varied opportunities and true learning experiences
- allows for growth and natural progression from school to community
- needs improvement to ensure full inclusion throughout the province

3. **SPECIAL SERVICES AT HOME (SSAH) IS WORKING BUT NEEDS IMPROVEMENT**

- allows for families to keep their loved ones at home and in the community
- allows for families to self administer if they so choose
- allows for individuals to grow in a loving, caring, nurturing environment
- allows for full participation in community (provided that the necessary supports are in place)
- makes use of community resources

IMPROVEMENTS NECESSARY:
- easier access
- annualize funding
- needs to fully meet the needs of individual and not be capped at a maximum level
- based on needs, not deficits (families do not want to degrade their loved ones by portraying them as dependant, behavioural, financial burdens)
- cost of living index for supports and for wages for support workers
- develop infrastructure to allow for networking of families and provide avenues to access qualified, reliable workers
- more freedom to use funds according to support requirements
- provide continuing supports past age of 18
- continue to support individuals who move out of the family home according to life's normal progression
- ability to combine services from various ministries to facilitate accountability
- decrease the amount of money eaten up by administrative charges; therefore increasing direct support available
- a natural progression from SSAH should be Fully Individualized Funding
- identify those projects that are working and expand on them

4. **FOUNDATIONS PROJECTS (some like Huron, Kitchener-Waterloo and Sarnia are working, others like Perth are not)**

- ensure funding is being used to support individuals in community not to expand day programs
- improve system for monitoring use of funding
- identify funding as individualized
- prevent agencies from using funding to increase their base budget as this does not necessarily increase the amount of supports in the community
- continue / expand independent facilitation

5. **GROUP HOMES AND DAY PROGRAMS**

- are segregated programs and cannot provide necessary supports for full participation in community
- after all attempts have been made to introduce individuals to community based supports, group homes and day programs will continue to be necessary for those individuals who choose to remain in the support system that has been developed for them
- group homes and day programs require improvements to ensure rights and safety of the individual

6. **OTHER SUPPORTS AND SERVICES**

The following programs / services have been identified to build upon. However, it must be noted that there is no lone program or service in Ontario that incorporates all elements necessary to generate full inclusion for all.

- Centre for Independent Living in Toronto (C.I.L.T.)
- Options at F.S.A. Toronto
- NABORS
- DIAHAGO
- Community Living St. Marys and other Community Living Associations which provide true person centered planning and supports
- Windsor-Essex Brokerage for Personal Supports
- Accreditation Ontario Courses
- Youth En Route
- McMaster University-matches individuals with other students

4. How should a reasonable level of government funding for an individual be determined?

DETERMINING A REASONABLE LEVEL OF GOVERNMENT FUNDING IS A TASK FOR A HIGHLY INFORMED TECHNICAL GROUP, TAKING INTO CONSIDERATION: INDIVIDUAL NEEDS, GOALS & DREAMS; LESSONS LEARNED IN OTHER JURISDICTIONS; USING QUALITY OF LIFE AS THE TRUE INDICATOR WHILE ENSURING FULL PARTICIPATION IN COMMUNITY.

THIS THEME IS SUPPORTED BY THE FOLLOWING COMMENTS FROM OUR RESPONDENTS

- task for highly informed technical group which should use experiences of other jurisdictions in Canada and throughout the world

Possible tools/mechanisms to assist that group include:

- using existing generators such as the Educational System I.S.A.; SSAH; combining the two generators to develop a level of funding that once allocated will not be lost if it is not used as people's lives change constantly and therefore their needs vary from day to day
- linking individualized planning and funding to help secure better support and help society learn better ways to include people
- considerations to be made include:
  - flexibility
  - equity
  - unit costs of support specific to needs based on strengths, preferences, necessary support required to live and actively participate in the community
  - existing supports i.e. aging parents not always be available
  - non-pd supports are not equally available throughout the province, therefore they cannot automatically be factored into the equation
  - health concerns
  - geographic area and availability of and distance to supports (differ from small town to large cities)

- travel costs to & from services
- accessibility of services
- develop a system by which individuals who are able to engage in employment and try to better their status are not taxed at a rate of 100% as is presently the case (this does not promote innovative thinking or taking risks)
- suggestion that a local network be established to pool any extra resources to enable fluctuations in needs to be shared by others who might need more at a specific time, i.e. increased need due to times of transition; ailing family member; personal emergency
- community supports already available or which could be developed   (i.e. United Way, Big Brothers/Sisters, Lions and other service clubs)

5. **Services are changing in Ontario for people who have a developmental disability. What would you like to see happen?**

ALL INDIVIDUALS REGARDLESS OF THEIR DIFFERENCES HAVE A RIGHT TO BE ACTIVE, CONTRIBUTING MEMBERS OF SOCIETY, THEREFORE THE IMPLEMENTATION OF FULLY INDIVIDUALIZED SUPPORTS AND FUNDING IS ESSENTIAL. SERVICES MUST BE FUNDED BASED ON INDIVIDUAL NEEDS UTILIZING AVAILABLE DOLLARS TO BE SPENT ON DIRECT SERVICE RATHER THAN ON AGENCY INFRASTRUCTURE SUCH AS HIGH SALARIES & BENEFITS OF MANY LEVELS OF MANAGEMENT, BUILDINGS AND MAINTENANCE OF THOSE BUILDINGS, VEHICLES ETC.

THIS THEME IS SUPPORTED BY THE FOLLOWING COMMENTS FROM OUR RESPONDENTS

- # FULLY EMBRACE CITIZENSHIP
- annualized individualized funding that:
    - is specifically allocated to the individual
    - is adequate to meet the needs of the individual
    - is portable
    - is flexible
    - is responsive to change
    - is available from one single funding source
    - offers true choice
    - does not discriminate against one population or another
    - is easily accessible
    - is stable and constant
    - provides for the necessary infrastructure to enable individual advocacy and networking; family networking & sharing
    - has clear and consistent criteria for allocation
    - is legislated

- access to independent planning / facilitation
- whole life planning not just bits & pieces with different funding generators
- fully inclusive community activities
- fully inclusive education
- full adoption of "In Unison" strategies & commitments
- immediate implementation of an individualized funding model and necessary infrastructures to support full participation in community
- stop forcing individuals to leave the comfort and security of their homes in order to access funding necessary to fully participate in their chosen community
- abolish waiting lists for services
- direct funding to individuals/ families/ supportive circles or mini boards instead of to agencies
- legislated appeals mechanism
- stop making/having demands/expectations on/of a person with a disability that would not ordinarily be made of someone without a disability
- work with other ministries to combine support funding into one pot
- eliminate conflict of interest as agencies fail to meet the needs of the individuals they are funded to support because of the needs of unions, staffing, management policies, maintenance and managing budgets
- allow greater flexibility in use of the support dollars—looking at a full year's budget rather than a monthly breakdown to be used as necessary according to need on any given day
- decrease the amount of bureaucratic paperwork
- develop a mechanism by which Ministry can inform individuals / families of increase in funding not just agencies
- provide assistance to individual / families to gain access to and/or manage increased funds
- educate service system regarding value of involvement and planning of those who truly know the needs of the individual
- implement consistent processes and guidelines across the province to ensure equal access to services for all
- stop dictating fee for service to allow the most beneficial use of supports
- provide more specialists trained in disabilities to eliminate waiting lists for professional services (i.e. psychologists; pediatricians) to facilitate necessary supports when needed not 6 months or a year later

- make those specialists available at an early age to follow an individual through the years to enable the professionals to learn from/about the individual and as a result be able to give more consistent advice and assist the development of more consistent individual program / educational plans
- improve existing services to truly protect and support individuals who wish to avail themselves of those services (develop policies around use of restraints; improve supervision; protect human rights at all times)
- protect the privacy of the family/individual—eliminate need for lives to become an open book for all to see in order to access services
- stop pitting families against one an another
- stop making individuals / families fight for support—this wastes valuable time and energy which could be used more productively to support the individual
- implement a stronger more effective ODA
- stop pitting families against agencies and vice versa
- implement innovative strategies for residential supports
- provide incentives for service providers to move toward more individualized options for everyone
- develop community capacity building by removing all barriers, providing necessary supports and recognizing the community as the vehicle for change
- recognize individuals/ families/ support networks as valuable resources

WHY?

EVERY INDIVIDUAL HAS A RIGHT TO BE AN ACTIVE PARTICIPANT IN SOCIETY AND AN INDIVIDUALIZED FUNDING MODEL ENABLES SUPPORTS TO BE INDIVIDUALIZED ACCORDING TO AN INDIVIDUAL'S STRENGTHS AND NEEDS, THUS FACILITATING FULL PARTICIPATION IN THE COMMUNITY

- current programs do not suit everyone's needs & interests
- current programs foster segregation not inclusion
- individualized funding allows for ownership of one's own life
- is cost effective,
    - eliminating duplications of services (maintenance of buildings / vehicles of different agencies)
    - reduces large dollar figures skimmed from top of funding to provide for many many large salaries

- allows for community to learn and grow thus increasing awareness, understanding & tolerance
- provides more opportunity to explore new ideas, experience new things, develop various relationships within the community
- relieves stresses on families/networks as they can truly plan for the future
- recognizes individual as a participant and contributor rather than as a leech
- portability increases ability to adapt to changes as aging/dying parents and wanting to be closer to siblings, other supportive relatives
- provides consistency & continuity as supports can be seamless

HOW?

FOLLOW THE REPORT OF THE ONTARIO ROUND TABLE ON INDIVIDUALIZED FUNDING……MAY 2000

- redirect funds away from bricks & mortar to other innovative residential and community supports

WHEN?

IMMEDIATELY

HOW LONG?

AS LONG AS IS NECESSARY, SOME INDIVIDUAL'S NEEDS FOR SUPPORTS WILL DIMINISH WITH EXPERIENCE WHILE OTHER INDIVIDUALS WILL REQUIRE A LIFELONG COMMITMENT FOR SUPPORTS

- Developmental Disabilities cannot be "fixed" but individuals with developmental disabilities can be supported to live more independently and more productive lives in the community with the necessary level of support. There are some individuals whose support requirements will diminish over time, other individuals whose support requirements will remain constant and then there are those who will require more as they grow older

6. What do you think are the priorities the government should address?

1. THE IMPLEMENTATION OF AN INDIVIDUALIZED FUNDING MODEL OF SERVICE DELIVERY TOTALLY SEPARATE FROM THE CURRENT SERVICE SYSTEM

- develop adequate, portable, convertible, equitable individualized funding available to all who want it
- allow for direct funding or for funding to flow through a payment transfer agency allowing for free choice of that agency
- trust individuals/families
- recognize support networks
- provide necessary infrastructure supports to ensure the success of individualized funding
- develop training opportunities for independent planners / facilitators

2. IMPROVE THE CURRENT SERVICES TO PROVIDE A SAFE AND HEALTHY SUPPORT SYSTEM THAT FULLY PROTECTS THE RIGHTS OF THE INDIVIDUAL AND ALLOWS FOR MAXIMUM COMMUNITY PARTICIPATION

- raise ODSP
- be more realistic as to costs of needs to prevent individuals from living in poverty
- fund all aspects of disability supports according to true need (incontinent supplies; specialized equipment etc)
- provide more affordable housing and support innovative living/housing arrangements
- expand SSAH in preparation for true Individualized Funding model
- provide sufficient funding to eliminate waiting lists for any services
- provide services without forcing an individual to leave home

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- create linkages to other ministries to enable seamless supports
- develop single access entry into service system and for accessing funds
- provide safety net to catch individuals falling through the cracks (those who do not qualify for other supports but require disability supports)
- ensure adequate supports before closing institutions
- fully prepare and involve individuals / families in the entire process before closing institutions and ensure adequate individualized supports are in place before moving individuals
- encourage individuals to choose community participation instead of segregated programs
- recognize that group homes and day programs are mini institutions that do not foster community participation and phase them out
- mandate that all attempts be made to move to more inclusive use of supports
- provide funds for community capacity building
- provide incentives for service providers to develop innovative support strategies only after all needs have been met
- ensure individuals / families retain their dignity
- treat individuals / families with respect; allow them to promote self esteem and their importance in society rather than make them feel like they are a nuisance/encumbrance
- provide funding and necessary supports to enable families to hire qualified & reliable workers

7.   Is there anything else you would like to say about the ideas in this discussion paper, or ideas not included in the paper that you feel are important?

INDIVIDUALS / FAMILIES/ SUPPORT NETWORKS ARE PLEASED THAT THIS PROCESS HAS BEEN UNDERTAKEN. FAMILIES HAVE BEEN VOICING THEIR OPINIONS FOR MANY YEARS THAT THE PRESENT SERVICE DELIVERY SYSTEM IS BROKEN; BUT NOW INSTEAD OF ASKING THAT IT SIMPLY BE FIXED, THEY ARE ASKING THE MINISTRY TO LISTEN TO THEIR COLLECTIVE VOICES AND MAKE REAL POSITIVE CHANGE BY DEVELOPING A NEW MODEL FOR SERVICE DELIVERY THAT ENABLES INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES TO TAKE THEIR RIGHTFUL PLACE IN SOCIETY, A RIGHT WHICH HAS BEEN DENIED THEM FOR FAR TOO LONG!

INDIVIDUALS / FAMILIES / SUPPORT NETWORKS WISH TO REITERATE THE IMPORTANCE OF INVOLVING THE CONSUMER OF SERVICES IN ALL ASPECTS OF POLICY DISCUSSION AND DEVELOPMENT AS THEY ARE THE RECIPIENTS OF THOSE DECISIONS. IF YOU DON'T LIVE THE LIFE, ASK THOSE WHO DO AND RESPECT THEIR INPUT!

- not everyone was informed of the entire process of this transformation and as consumers they should have had more detailed information
- there is a fear that the proposed time line is too short; but while families need help now, it is also important to take the time to make changes the right way to ensure the success of change
- families are asking that the government and service providers trust individuals/families/support networks to represent their needs honestly, respectfully, with only the best interest of the individuals with disabilities at heart
- it is important that for true change to take place it is important to involve all areas of government; all levels of government and the public sector
- learn from previous mistakes; segregation has created a population dependent upon services; learning can only take place through real experience; policies created without the input of those involved will

continue to negatively impact those individuals because unless you live the life, you will never know what it is truly like

IN CONCLUSION, THE MINISTRY MUST ASK THREE QUESTIONS:

1.) TO THOSE INDIVIDUALS WHO HAVE EXPERIENCE FULL INCLUSION AND THEIR FAMILIES—ARE YOU WILLING TO ACCEPT SEGREGATED SUPPORTS AND MOVE BACKWARDS?

THE ANSWER IS A LOUD AND DEFINITIVE **NO!**

2.) CAN THIS MINISTRY TAKE BACK WHAT ANOTHER MINISTRY HAS DEEMED ESSENTIAL (INDIVIDUALIZED SUPPORTS IN THE EDUCATION SECTOR) FOR COMMUNITY PARTICIPATION?

THE ANSWER TO THAT QUESTION IS: **NOT MORALLY AND IN GOOD CONSCIENCE.**

3.) IS THERE ANYONE WHO HAS INDIVIDUALIZED FUNDING ASKING THAT THE MINISTRY BRING BACK SEGREGATED PROGRAMS AS THE ONLY OPTION?

THE ANSWER TO THAT QUESTION IS: **NO!**

THEREFORE, THIS GOVERNMENT CAN ONLY MOVE FORWARD, INTO THE FUTURE OF FULL CITIZENSHIP FOR EVERYONE! HOW CAN THIS GOVERNMENT BEST ACHIEVE THAT GOAL?

THE ANSWER TO THAT QUESTION IS: **BY IMPLEMENTING AN INDIVIDUALIZED FUNDING SERVICE DELIVERY MODEL!**