

Transforming Services in Ontario for People who have a Developmental Disability

Preliminary Discussion Paper

October 2004

Contents

Introduction: The Purpose of this Paper	1
A Brief History of Developmental Services	4
Vision	8
Principles	8
Dignity and Respect	9
Building on Community	9
Fairness and Responsiveness	9
Accountability	10
Practicality	11
Sustainability	11
Challenges We Face	11
Roles and Responsibilities	12
Characteristics of Quality Support	12
Models of Funding	13
Legislation and Policy	13
Stresses on the Current System	14
Questions for Discussion	15
Appendix A: Partnership Table Membership	18

Introduction: the Purpose of this Paper

The government has worked with families and communities for more than 50 years to create supports and services for people who have a developmental disability. Today, most of these supports and services are funded by the Ministry of Community and Social Services and delivered primarily by approximately 370 board-operated, non-profit, developmental services providers.

Because of this support, people who have a developmental disability usually have far more opportunities to participate in the community than in the past. Still, there is a great deal of work to do. Many people and their families do not receive all the support they need. Changes in life, such as birth or graduation from school, are usually happy and exciting times for families. For families of a person who has a developmental disability, these often become times of worry, disappointment and struggle. Because people do not always get the support they need, they are often not able to take part in community activities. People sometimes live lonely lives without much to do. Many people have no opportunity to share their personal talents with others in society or contribute to their community.

Government continues to spend more and more money to provide supports to people who have a developmental disability to address these issues. The available supports are still inadequate to enable families and individuals to cope with the challenges that they face every day of their lives. On May 18, 2004, the Ontario Budget announced that “the Province will be transforming services for people who have a developmental

disability in order to create an accessible, fair and sustainable system of community-based supports.”

Following this announcement, the Ministry of Community and Social Services invited a group of provincial organizations to form the “Joint Developmental Services Sector Partnership Table”. The Partnership Table has representatives from self-advocate, family and service provider associations and the Ministry of Community and Social Services.

The Partnership Table has prepared this discussion paper to raise questions that are intended to help people share their own ideas. The Partnership Table will use this paper to consult with their members and other interested parties. Feedback on this discussion paper will help the Ministry to prepare a draft plan to transform services in Ontario for people who have a developmental disability. Once a draft plan has been prepared, the Ministry will hold a broad public consultation about the draft plan. Through this consultation, they will invite comment and talk to individuals, families, people who provide supports and services, and other people from other parts of society.

The ideas in this document are presented for the purpose of discussion only and do not represent proposed directions or policy on the part of the Ministry of Community and Social Services.

This document contains a list of questions, beginning on page 15. Following is a shortened version of the questions presented as an introduction to this discussion paper.

- 1. What should be the roles and responsibilities of different parts of society in supporting individuals who have a developmental disability?**
- 2. What strategies and resources would help individuals receive seamless supports throughout their lives, including points of transition?**
- 3. What supports and services that are currently available work well and should be built on for the future?**
- 4. How should a reasonable level of government funding for an individual be determined?**
- 5. Services are changing in Ontario for people who have a developmental disability. What would you like to see happen?**
- 6. What do you think are the priorities the government should address?**
- 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?**

A Brief History of Developmental Services

Before the 1950s, few community services existed for people who had a developmental disability. The choices at that time were to live in an institution away from one's family and community or to live in the community, usually with one's parents, with little or no formal support.

By the 1950s, family advocacy groups had started to emerge across the province. These families began to ask why the kind of services available in the institutions could not be provided for their sons and daughters that lived at home. As the family groups and the associations they formed grew through the 1950s, 1960s and 1970s, they worked with government to create a variety of programs: special education programs, sheltered workshops, group homes, recreation and respite programs, to mention just a few. Also during the 1970s, people who had a developmental disability began to organize to ensure that they had a say in how services and supports evolved. The first provincial self-advocacy group, People First Ontario, formed in 1981.

Originally, most programs were funded by the Ministry of Health which operated the 16 large institutions that existed at the time and which also funded the emerging community services. Over time, the number of community-based services increased considerably. By 1974, it was clear that community-based services would be the option of choice for the future and the Ministry of Community and Social Services took over responsibility for Developmental Services. The government began to reduce the number

of people living in institutions in the 1970s. In 1987, the Ministry of Community and Social Services released a plan for the future of Developmental Services, *Challenges and Opportunities: Community Living for People with Developmental Handicaps*. This plan was to create community services throughout Ontario to support people who had a developmental disability. *Challenges and Opportunities* also set a plan for closing all the institutions in Ontario within 25 years. On September 9, 2004, the Minister of Community and Social Services announced that the three remaining institutions for adults who have a developmental disability would be closed by March 31, 2009.

Many of the services we rely on today were created at a time when families were still asking the question, “Why can’t the services available in the institutions be provided for people who live in the community?” While based in the community, many of the emerging programs were modeled on those previously available in the institutions and, as a result, contained institutional elements in their design. Service providers have worked to redesign programs, to keep them up to date with changing expectations; change, however, has sometimes been difficult.

Many of the early community-based programs were created to provide people with a safe place to live or spend their day under the care and supervision of a service delivery agency. Some programs were designed to assist people to develop greater independence that would eventually lead to the person being included in regular community settings and activities. For many, these programs continue to provide valuable services and are the preferred option for support.

Many other individuals and families are looking for support options that start with inclusion. There has been a growing demand for programs such as inclusive education, supported employment and a range of more individualized approaches, including an individualized funding model. Many families and individuals welcome the security and certainty that can come from participation in traditional community-based services. For others, individualized funding (where funding is given directly to the individual or family) is seen as an essential mechanism for enabling citizenship as they feel it allows an individual or family to purchase support in the community and to have greater control of their lives without having necessarily to participate in traditional programs. The Ministry provides funding directly to families through the Special Services at Home program and a few pilot programs.

Access to individual life planning has long been seen as an important feature of service delivery as it is a way of directing the delivery of supports and services to best meet the needs of an individual. For a growing number of people, independent planning that is not tied to a service delivery agency is seen as an important way of connecting people to community resources and supports.

Families and individuals continue to have different preferences with respect to how they receive funding and services - whether through traditional services or individualized funding. Regardless, families and individuals want to be assured that they will receive the support they need when they need it. This assurance has been referred to in different ways: entitlement,

“as-a-right” funding or mandatory funding. For government, the question is, what is a reasonable level of support for an individual and how can this be determined?

Changes in Developmental Services in recent years have been influenced by a focus on citizenship. Today it is recognized that people who have a developmental disability have all the rights of other citizens to participate in their community. In the past it was the responsibility of the person who had a developmental disability to change in order to “fit in” to community. Today we recognize that society also has a responsibility to change in order to support all its citizens and remove any barriers to participation in community.

In recent years, the government has introduced policies and legislation that support the idea of citizenship. For example, *The Ontarians with Disabilities Act* (ODA) was passed in 2001. This act recognizes the citizenship rights of people who have disabilities and works to remove and prevent barriers that would keep people from participating in society.

The idea of citizenship and enabling people to have control over what they do with their lives was central to an agreement struck by the Federal/Provincial/Territorial Social Services Ministers in 1998. The agreement, titled *In Unison: A Canadian Approach to Disability Issues*, outlined a vision of full citizenship and full participation for people with disabilities in all aspects of Canadian society. The document also recognized the role of government and all other segments of society in supporting the citizenship rights of people with disabilities.

The vision of citizenship, as described by *In Unison*, matches the vision that many see for Developmental Services in Ontario. To build on the work of the *In Unison* agreement, the Joint Developmental Services Sector Partnership Table has adapted the vision of *In Unison* to guide this consultation process.

Vision

Persons with disabilities participate as full citizens in all aspects of Canadian society. With commitment from all segments of society, persons who have a developmental disability will maximize their independence and enhance their well-being through access to required supports and the elimination of barriers that prevent their full participation.¹

This vision affirms the importance of full participation in society for persons with disabilities. It recognizes the need for specialized services for people who have a developmental disability in order to make sure they have the same opportunities as other Canadians.

Principles

Changes in Developmental Services and supports will need to be based on a clear set of principles. Following are principles that have been proposed by the Partnership Table.

¹ Adapted from *In Unison: A Canadian Approach to Disability Issues (1998)*.

Dignity and Respect

- Recognition and respect for the citizenship rights of people who have a developmental disability.
- Recognition of the dignity that comes from people planning and making important decisions about their own life.
- Respect for people's faith and culture in the provision of services.
- Respect for an individual to receive services in French in all areas of the province designated under the *French Language Services Act*.²

Building on Community

- Recognition that community is able to provide the things that a citizen needs to participate in society and that a person who has a developmental disability might need support in accessing these community resources.
- Commitment to involve stakeholders, particularly individuals who have a developmental disability and their families in the planning, policy development, implementation and monitoring related to supports and services for people who have a developmental disability.

Fairness and Responsiveness

- Equitable access to funding and supports so that people with similar

² Since the proclamation of the *French Language Services Act* in 1986, the government has been working with families, communities, associations and service providers to provide quality services in French in all designated areas of the province.

needs receive comparable levels of support across the province.

- Funding for supports and services that is fair, responsive and flexible, and that provides certainty for individuals, families, service providers, and government.
- Funding for supports that is portable. This means funding that allows the person choice in where and with whom they live or who provides the supports, moves with the person if they move from one community to another within the province and is responsive to transitions in a person's life (e.g. moving away from a family home, becoming a senior citizen).

Accountability

- Recognition that all sectors of society are responsible to make sure that people who have a developmental disability receive the support they need to participate in the community and that barriers to participation are removed. This includes families, governments, business people, service clubs, community organizations, citizens, and others.
- Access to appropriate independent appeal mechanisms for people who have a developmental disability for the funding they receive.
- Commitment to the most effective use of resources, including community, government and family resources.
- Accountability of government and service providers to provide quality and choice to recipients of service.
- Evaluation of Developmental Services based on the quality of personal outcomes for people receiving support.

Practicality

- A developmental services system that is easy for individuals and families to understand and navigate.
- Transformation of Developmental Services based on the things we have learned in Ontario and other places about the best ways to support people who have a developmental disability to participate in society as full citizens.

Sustainability

- Sustainable supports that offer flexibility and increased choice, and that stimulate innovation and creativity within available resources.
- A system that is sustainable to inspire confidence and provide certainty and reliability for individuals, families, and service providers. A system that recognizes that government funding is not unlimited and that sets priorities.

Challenges We Face

The following will look at areas of change that the Partnership Table has considered for discussion including:

- Roles and Responsibilities
- Characteristics of Quality Support
- Models of Funding
- Legislation and Policy
- Stresses on the Current System.

Roles and Responsibilities

Changes in Developmental Services have moved through phases:

1. an institutional phase – institutions responsible for the care of individuals;
2. a community services phase – community service agencies responsible for the care and support of individuals;
3. a citizenship phase - all parts of society have a responsibility to ensure that supports are provided and barriers to community participation are removed.

Through each of these changes, the number of people with roles and responsibilities has grown as people have become increasingly connected to their community and the participation of families in an individual's life has often increased. Today, we are calling on all members of society to participate in supporting individuals who have a developmental disability. This suggests that clarification is needed with respect to roles and responsibilities.

Characteristics of Quality Support

The Partnership Table has discussed five characteristics to describe quality supports and services. Such characteristics might be used to guide changes to the existing services and to assist in the creation of new supports and services.

These characteristics are presented for discussion:

- sufficient - adequate to meet the needs of the individual;
- secure/certain– available for as long as the support is needed;

- individualized – funded and delivered in a way that meets the individual strengths, needs, interests, goals and relationships of the person;
- accessible – available when needed and easy to understand; and
- portable – funding that allows the person choice in where and with whom they live or who provides the supports, moves with the person if they move from one community to another within the province and is responsive to transitions in a person’s life (e.g., moving away from a family home, becoming a senior citizen).

Models of Funding

The demand for services and support is greater than the supply. Waiting lists are lengthening. Additional funding provided over the past five years has quickly been absorbed. And some people in similar circumstances receive different levels of support.

Some people have been pressing for more individualized funding as a way of achieving more choice and control over the supports and services they receive. Others express satisfaction with the current transfer payment model for service delivery. Some prefer a combination of both models.

Legislation and Policy

The *Developmental Services Act*, which guides the allocation of most of the government funding in Developmental Services, was enacted in 1974 and has since been amended. It was designed to support the types of services that were emerging at the time it was created. Likewise, many of the existing regulations and policies under which the Ministry operates were

developed to support the community-based system of services as envisioned in the 1970s.

Stresses on the Current System

The current support system is under extraordinary stress. Demands for services continue to grow, as do waiting lists, and funding for wages and other costs have not kept pace with inflation.

Questions for Discussion

The material in this document is intended to provide an overview of the history and some of the current challenges facing Developmental Services. It also suggests a Vision and a set of Principles that might be used to guide future changes. The main purpose of this document, however, is to gather the thoughts and ideas of people from across Ontario to advance the discussion and to prepare for a more extensive public consultation that the Ministry of Community and Social Services will hold on a new plan to transform services in Ontario for people who have a developmental disability.

Ideas and suggestions from all groups or individuals are welcome. The following questions are offered as a guide for providing your ideas and suggestions. Feel free to answer any or all questions. You may also provide suggestions not related to the questions asked here.

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

For example, you may want to consider:

- What are the roles and responsibilities of:
 - Individuals who have a developmental disability
 - Families
 - Governments
 - Service providers

- Other parts of society, such as business, faith-based communities and cultural organizations, service clubs, and voluntary organizations?
- What changes are necessary to encourage the above players to work together to carry out their roles and responsibilities?

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

For example, you may want to consider:

- Transition into and out of the school system
- Into employment and through changes in employment
- Into senior years

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

For example, you may want to consider:

- Special Services at Home program
- Day programs
- Foundations program
- Individualized funding

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

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

For example, you may want to consider:

- What do you need?
- Why do you need it?
- When do you need it?
- How long do you need it?

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

For example, you may want to consider:

- Housing
- Day supports
- Special Services at Home program
- Creating linkages to other ministries
- Funding for community capacity building
- Funding and support for innovation

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?

Appendix A: Partnership Table Membership

Membership on the Joint Developmental Services Sector Partnership Table includes designated representation from:

- the Provincial Network on Developmental Services (Community Living Ontario, Faith/Culture, Great Lakes Society, Metro Agencies Representatives Council, Ontario Agencies Supporting Individuals with Special Needs)
- People First Ontario
- Family Alliance Ontario
- Ministry of Community and Social Services

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