

## Community Living Ontario Keys to Transformation

# Recommendations for Transforming How Society Provides Support to People Who Have an Intellectual Disability

#### Introduction

On May 18, 2004, the Minister of Finance announced in the Provincial Budget Speech 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."

For the past number of years, Community Living Ontario has been working to describe the changes that are occurring in society with respect to the way that people who have an intellectual disability are included and supported in society. We have also worked to describe the changes that must occur in social policy to enhance the citizenship rights of people who

have an intellectual disability. We have referred to this as our Citizenship Agenda.

Over the past several weeks, Community Living Ontario has held 5 events to meet with our members in different parts of the province to gather their ideas and recommendations with respect to the Preliminary Discussion Paper, *Transforming Services in Ontario for People who have a Developmental Disability.* We have also received a number of written submissions from our members informing us of the changes they would like to see as part of the transformation process.

Community Living Ontario has prepared a document, *Report of Community Living Ontario Regional Federation Days*, which is a companion to this report. The Federation Day report provides an overview of the Community Living Ontario Citizenship Agenda and an outline of the comments and recommendations from the five events. The information contained in the Federation Day report, our work on the Citizenship Agenda and the written submissions from our members have all been used in preparing the following set of recommendations.

### Community Living Ontario's Citizenship Agenda

Since the 1970s, the focus within the Developmental Services sector has been on developing programs and services that would provide people places to live and spend their day. The programs and services have

typically provided those supported with an improved quality of life. Often, however, these services and programs provided people a substitute for real community experiences. In fact, over time, many people have developed a dependency on the sheltering services that have been provided to them and have little capacity or few opportunities or relationships that would assist them to effectively participate in community life. People have told us that sometimes these programs get in the way, create barriers to real participation in community. Too often, government policy and funding as well as the structures of programs respond to old assumptions about the role that people who have an intellectual disability play in our society and do not promote the outcomes that individuals and families want.

These approaches were developed based on the best thinking of the time. They have served many people well and have paved the way for an evolution in thinking that has allowed people increasingly greater access to the community. Further, for many who have come to rely on these programs, they will continue to provide valuable services for many years to come and should be adequately supported through policy and funding in the future until such time as they are no longer needed.

The key message within the Community Living Ontario Citizenship Agenda is that it is time to reconsider the main focus or core business of the Developmental Services sector. The last time that the Ministry undertook a comprehensive planning process was in 1987. That plan is described in the document *Challenges and Opportunities*. The core business of Developmental Services envisioned in that plan was the development of a comprehensive system of programs (group homes, day support programs,

etc.) throughout the province that would provide people who have an intellectual disability places to live and spend their days.

The current transformation process will fail if it does not adopt a new direction - a new vision of the sector's core business. The government has committed to transform the sector to a system that is fair, accessible and sustainable. To ensure fairness, we must respond in an equitable way to those individuals what are currently not being supported or are undersupported. The current system cannot support more people without additional funding. Over the past decade, the sector has found all the efficiencies possible and current programs are not going to become less expensive to operate. Increased congregation - forcing more people into each group home or day program - runs contrary to all social trends toward inclusion, is morally objectionable and, as history has demonstrated, does not ultimately lead to lower costs.

Ensuring fairness by providing all those that are currently not supported or are under supported with a comprehensive set of programs as envisioned by the current core business description would take more than a three-fold increase in funding and is not, in fact, what many are seeking. Even if the government was to take the unlikely step of increasing funding by this degree in order to respond to those on waiting lists, there is no reason to think that demands on the sector would not continue to grow. We could find that supporting many more people at much greater expense could make long-term sustainability very unlikely. Clearly a new approach must be adopted.

#### **A New Core Business**

The new core business that Developmental Services should focus on has two elements:

- enabling the community to include people who have an intellectual disability; and,
- enabling the person to participate in spite of their disability.

This new core business will shift Developmental Services increasingly away from a primary focus on the provision of programs and services that house and occupy people's day, to a primary focus on community development, community capacity for social inclusion and providing individual support for community inclusion.

This does not suggest that we will abandon the current work of delivering these legacy programs. The Ministry has talked about a transformation process that will take place over a period of 20 to 25 years and we agree that true transformation will take something in that order of time to achieve. We believe that purposeful, focused changes of direction that are initiated now will lead, as they unfold, to dramatic changes over that period of time. We have likened this to a ship crossing an ocean - if we are to make a small degree change in course now, by the time we have crossed the ocean, we will end up in a very different place than we would originally have landed.

Of course we are not suggesting that we ignore the real needs of individuals today. We must continue to work to ensure that those currently being supported have access to planning aimed at establishing greater connection to people and supports within their community and we must respond promptly to those waiting for services through planning and new investments in funding.

People who have an intellectual disability will require various kinds and degrees of support throughout their life. The strategic notion behind Community Living Ontario's recommendation is for government to provide the policy framework, funding and support that is necessary to ensure that communities and families are enabled to provide many of the needed supports in natural community settings, rather than placing people into disability support programs. The work of the sector and the priorities for government funding would become, increasingly, to support families and communities in these roles. The balance of this document will describe the strategies and specific policy and funding changes that Community Living Ontario feels must occur to facilitate this change.

#### **Strategic Considerations**

#### **Government Responsibility**

Building relationships in the community and learning skills to ensure an increased level of independence will only occur when a person is actively part of the community. We must, at all times, start with an assumption of

inclusion and not continue to create support options that people will either grow dependent on or will later need to "transition" from.

The first strategic consideration must be to ensure that people live their lives, beginning at birth, embedded in family and community life. As long as we fail to support families of babies that have an intellectual disability, and as long as they are led to believe that services can do a better job of nurturing and supporting their children then they can, families will develop dependency on government programs. As long as we maintain segregated pre-school programs, we foster dependency on specialized segregated programs as children enter school. As long as we segregate children throughout their school life, we deprive them of the education necessary to develop as integrated and independent adults and we simultaneously deprive other students of the experience of learning necessary to assist them in the inclusion of people who have an intellectual disability in their lives and communities. By segregating throughout school life, we cut off critical relationships necessary for success in adult life.

As long as students leave the education system with an expectation of segregation and dependency on disability services, little will change, transformation will not occur and the desire and ability that people have to be included and to make a contribution will not be realized. The transformation process will fail if we do not reform our early child-hood supports and education system to ensure that children are included from the beginning.

Strategic Consideration #1 – The transformation process will fail if the Minister of Community and Social Services attempts to work in isolation of the other Ministries. The preceding description demonstrates the implications for the Ministry of Community and Social Services if the Ministry of Education and the Ministry of Children and Youth Services fail to adopt a corresponding policy and strategic direction. Of course the same is true of many other Ministries upon which people who have an intellectual disability rely for support, including the Ministries of Health, Transportation, Attorney General and others. As long as any of these Ministries fail to adopt policy, funding and strategies to provide individuals and communities the necessary assistance to ensure inclusion, people will continue to be dependent on disability services that are typically provided through the finite resources of the Ministry of Community and Social Services.

Recommendation #1: That the Province adopts a policy direction that applies across government which recognizes that the core responsibility of government with respect to people who have an intellectual disability is to provide the policy and funding necessary to:

- enable the community to include people who have an intellectual disability; and,
- enable the person to participate in spite of their disability.

Further, the Province should develop strategies across government to ensure the implementation of this policy direction.

#### Legacy

**Strategic Consideration # 2** – Recognizing that this change will take a generation to fully implement the question must be asked, how we respond to both the real and critical need for assistance of individuals currently being supported as well as those of adults that are currently waiting for support. We will address these two groups separately.

**People Currently Being Supported** - Many individuals have grown up with the expectation that government funded programs and supports will be provided to them. Stripping people of supports that they have come to depend on would be immoral. It would not tolerated by families, by

Community Living or by society. Further, as it has been identified that there are not additional savings to be had through changes to these programs, implementation of future transformation strategies cannot expect that funding will be available from these programs to fuel the needed change - other funding will be required. In fact, it will be necessary to invest additional dollars in these existing programs to address the current stresses that they are experiencing and to ensure reasonable inflationary funding increases for as long as these programs exist.

Of course this is problematic! At present the current residential system funded by MCSS supports only about 35% of adults needing support but uses almost 70% of the available resources. This is a reality with which we will have to live as we evolve new approaches that do not extend this problem to future generations.

Recommendation #2: That MCSS maintain funding for existing legacy services until such time as they are no longer needed including a commitment to address current and future inflationary stresses that these programs experience.

Further, that the Ministry work with the sector to develop strategies to reform the existing system by providing individuals being supported with planning supports as described in this paper and opportunities for building skills and having relationships needed to ensure greater autonomy and greater community participation.

People Waiting for Services - The current system is heavily reliant on providing support through funded programs. At the current level of funding, the system is at capacity. Addressing the needs of those waiting for support will require new funding. The next section of this report, *Ensuring Accessibility, Fairness and Sustainability,* will outline a proposal for developing an entitlement to planning. Those waiting for support should be provided immediate access to planning as described below, aimed at assisting them to achieve the best support possible within the available resources of government, the community and their family.

Many of those waiting for services have grown up with an expectation of accessing traditional government funded programs. As a result of this expectation, it will be a challenge to develop strategies that do not put additional stress on the existing service system and lead to further imbalance in the fairness of funding allocations. The quality of the planning available to these individuals will be critical if we are to avoid this.

Recommendation #3: Given that the current support system is at capacity, new funding will be required to respond to those waiting for support. These individuals should have immediate access to planning support as described in this paper and access to additional funding as indicated by the planning process to address their support needs.

# Ensuring Accessibility, Fairness and Sustainability

The government has identified that the aim of the transformation process is to develop an "accessible, fair and sustainable" system for supporting the needs of people who have an intellectual disability. Community Living Ontario believes that this objective is entirely achievable and applauds the government for its initiative in attempting to bring about such a change. It must be recognized that it has taken us more than 150 years, since the government first undertook to build institutions, to get to where we are today. The change we all seek will not occur over night. The change that is needed will take a generation to fully achieve.

The policy directions described above will set us on the right path to make the changes that are necessary. In addition to this direction, there are a number of elements that must be put in place to support the change of direction. Following are some of the key levers of change that must be implemented.

#### **Entitlement to Individualized Planning**

This section of the paper, looking at an individual planning mechanism, will address each of the three key elements that the government has set out to achieve through this revitalization process, accessibility, fairness and

sustainability. The key challenges that must be considered when attempting to address these three elements are:

- 1. How does an individual or family find and access the supports that they need in the simplest way possible?
- 2. How do we assess an individuals needs, plan the supports that the person requires to address these needs and determine a funding allocation that is in keeping with the allocation that others might receive to address similar needs?
- 3. How do we ensure that overall allocations to all people requiring support can be addressed within a finite amount of government funding?

As a society, we have identified a desire and commitment to support this group of citizens through tax dollars. It is the role of government to do this in a most effective way, secondly, in an efficient way. Given this, it is not reasonable that people need to essentially beg for support or face extraordinarily long delays in accessing the support they require. There is broad agreement in the sector that we should be moving towards some form of entitlement to support for people who have an intellectual disability. In relationship to this, the challenges are:

- how do we ensure that the supports provided are appropriate and adequate to meet individual and family needs,
- what form should such entitlement take and,
- how to ensure sustainability of support for all who need them.

Community Living Ontario supports a move to entitlement. Such entitlement, however, should not be to particular residential or daily living programs or services. The needs of individuals are unique and could not be well served in this way. Nor should entitlement be simply to a predetermined amount of funding which, again, would not address widely varying support requirements of individuals and would not serve well those who need greater support. An approach is needed that takes into account, maximizes and supports the assistance that individuals can receive from family and community.

Community Living Ontario believes that all people who have an intellectual disability should have an entitlement to planning support. This planning support should be aimed at:

- assisting the individual to identify their unique aspirations, abilities and support needs;
- 2. working with the individual to identify existing family and community relationships and supports that might already exist to support them;
- 3. working to develop additional opportunities for relationships, participation and support within the community;
- 4. identifying what supports cannot be provided by family and the community and assisting the individuals to access them;
- 5. assisting the person to identify and access the government funding necessary to carry out their individual plan.

Such a planning mechanism is central to Community Living Ontario's recommended strategy for change. It will be complex to implement and will

require research and consultation beyond the details included in this paper. Following are some of the areas that must be considered in the development of such a mechanism.

#### **Accessibility**

A planning process as described in this paper could adequately address the issue of accessibility that the government has identified. Planners, who should be available in each community could provide a "single point of access" to support – a mechanism that government has worked to develop for the past number of years. To be clear, we are not proposing a mechanism like the single point of access developed through the Making Services Work for People (MSWP) initiative. That exercise was aimed specifically at trying to fit people into the existing service system. While people will continue, to different degrees, to access some of the existing services, the focus of planning, that will produce transformation and greater "inclusion", is more on community development and community access. In fact, Community Living Ontario believes that consideration should be given to dismantling the existing single point of access mechanisms in regions where it is determined to not be serving people well and using funding tied up in these mechanisms to build this new capacity.

#### Where should planners be based?

Research and consultation will be needed to address this issue.

Many people in the province are calling for a system of independent or unencumbered planning that operates independently of government or services providers. This is the predominant trend in

other jurisdictions. Such an approach has the clear advantage of avoiding any potential bias (or self-interest) that might exist with a planner connected to a current service and who might tend to direct people into existing programs. A similar bias could exist where the planner is tied to government; raising the concern that planning might lean towards options that avoid the need for funding even where that is not in the interest of the person.

Many who provide services have developed excellent individual planning mechanisms and feel confident in their ability to plan with individuals without demonstrating bias. Service providers are often understandably suspicious of external planning processes given how poorly some of the planning processes developed through MSWP have served people.

A model of planning exists in Western Australia similar to that proposed by Community Living Ontario. The Australian model has planners that work for the government. While there is much we could learn from that model, it would, under the present circumstances, place such planners in a conflict of interest. It would be inconsistent with the culture and practices here in Ontario to connect planners to government and that element would be deemed inappropriate by people in Ontario.

Regardless of the approaches adopted, Community Living Ontario believes that independent planning, not tied to services providers or government, should be available to all those who choose it.

#### **Skill Development**

The success of such a planning mechanism will rely heavily on the vision and skill of the planners in their ability to properly value and support individuals and families, assess needs, identify and develop community involvement and resources and have knowledge of the disability services available in the community. To ensure that such planning is effective and works well as a tool to develop and access supports, a comprehensive strategy for training and continually upgrading the skills of planners must be developed.

#### Fairness – Assessing individual Support Requirements

The Ministry has identified that, to ensure fairness in the allocation of funding that people receive, there must be a mechanism for assessing the needs of an individual in a way that can be compared to others receiving support. Community Living Ontario accepts that such an element is a normal requirement of accountability for government funding. We recommend, however, that such an assessment should not stand on its own, but be conceived within a planning mechanism.

There are many mechanisms used to determine allocations of government funding and benefits based on a variety of elements such as age, individual or family income, existing capital assets, etc. MCSS attempted a few years ago to develop the Levels of Support (LOS) tool to measure the level of disability of an individual and a similar tool was developed and is now being phased out by the Ministry of Education.

As singular criteria, none of these approaches provides a suitable tool for measuring need and allocating funding for the support of people who have an intellectual disability. A well conceived planning tool, however, will take into account other critically important elements as well as the various elements listed above. Planning should consider the person's aspirations and abilities and those of his/her family and community, opportunities and options for the inclusion and contribution, where the person lives, what resources does that person have available at home and through their family with respect to support and financing, does the person work and how much income do they have, what level support do they require for their disability related needs, and many other things.

Community Living Ontario believes that it would be possible, given appropriate research and development, to create an individual planning approach that would consider a wide range of elements. A comprehensive planning mechanism such as this could serve people well. In it, elements of the planning process could be reported in a consistent manner so as to be useful to compare the resulting funding needs of various individuals. The Roeher Institute has done some very preliminary work to consider such a mechanism and to consider how the various individual elements may be used in an aggregate to guide the distribution of government funding in a fair and consistent manner. Community Living is not ready to recommend this specific approach, but feels that it holds some promise and should be explored further. Such a mechanism could also address the issue of sustainability by providing a means of distributing a fair portion of

funding to each individual based on a predetermined envelope of funding identified by the government.

Recommendation # 4a – The government should establish entitlement to planning for all people who have an intellectual disability in Ontario. Such planning should be aimed at assessing an individual's needs and assisting the person or his/her family to identify and access the resources that they need within the community or through disability services.

Recommendation #4b – Such a planning mechanism should be available from birth. Funding and access to planning should be coordinated between the Ministries of Children and Youth Services, Education, Community and Social Services and Health, to ensure continuity throughout the person's life.

Recommendation #4c – The government should research and consult on the best ways for delivering planning, i.e. independent/unencumbered planning or through service providers. Regardless of the approaches adopted, all people should have access to independent planning if they choose it.

Recommendation #4d – MCSS should evaluate all access/single point mechanisms that currently exist using criteria set collaboratively with stakeholders and dismantle those single point of access mechanisms that are not serving people well. Resulting

savings should be redirected to the development of a planning mechanism such as suggested here.

Recommendation #4e – Assessment of an individual's needs and determination of a fair allocation of funding should be done within an individualized life planning process and not as a standalone exercise.

Recommendation #4f - Appropriate government ministries should explore a mechanism through which the broad considerations included in a planning process could be recorded in a fashion that provides consistent data. This data might then be used to ensure an effective and efficient system of support and resource allocations to individuals. Such data might be useful in developing a mechanism for allocating funding in an equitable fashion by creating more consistent rationales, based on collected data, for individual funding allocations.

Recommendation #4g – A strategy should be developed for training and maintaining the skills planners will require to carry out their task effectively.

#### Individualized Funding

Implicit in the planning mechanism just described is the need for individualized funding. The strategy that Community Living Ontario has outlined in this paper relies first on embedding people in community where

they can develop the connections and relationships necessary to live their lives. Nevertheless, funding is necessary to provide disability related support needs beyond what is currently available in an individuals community. Such funding should be allocated on an individual basis.

We should continue to unbundle funding that is currently tied up in existing programs. Individuals should have the flexibility to seek support from other services or other service providers and move from one community to another without losing the funding they need for support.

Recommendation #5 – Funding to carry out individual plans as described in Recommendation #4 should be provided on an individualized basis. Funding provided through traditional services should be unbundled and made portable so that a person who chooses to can seek or develop support from other resources of from a different service provider and move from one place to another without losing their supports.

#### **Income Support**

A message that Community Living Ontario hears strongly and consistently from people who have an intellectual disability is that Income Support through the Ontario Disability Support Program (ODSP) must be increased. The transformation process would be incomplete if it did not give serious consideration to addressing the level of income that ODSP Income Support provides and ensuring that future benefits are indexed to the cost of living

to ensure that erosion of benefits, as has been seen over the past decade, does not occur again.

As was identified in the preliminary discussion paper, the 1998, Federal/Provincial/Territorial agreement on disability supports, *In Unison*, provides principles and a citizenship framework that is worth considering as we develop a strategy for transformation in Ontario. In Unison described a framework of support for people who have disabilities with three main components: income support, employment supports and disability related supports. These three "building blocks" from In Unison should be incorporated into the transformation plan being developed in Ontario. When planning with an individual, all forms of available support should be considered including disability supports, ODSP income and employment supports and other supports available to children and adults. We should seek to ensure that all of these supports are coordinate under a policy framework that maximizes the benefit of each and lead to the best outcomes for people.

Recommendation #6 – ODSP Income Supports should be increased to make up for the significant reduction in benefits as compared to inflation over the past 12 years. Benefits should be indexed to the cost of living. ODSP income and employment supports and other supports available to children and adults should be reviewed in light of the transformation process to ensure that they work together in a seamless and effective fashion.

#### **Innovation**

To ensure transformation there must be strategies that stimulate, encourage and support innovation at the community level.

Recommendation #7 – the government should adopt a policy to actively encourage and fund innovation aimed at building community capacity for social inclusion and at supporting individuals who have an intellectual disability to participate in community life.

#### **Centres of Specialized Care**

As part of the transformation process, the Ministry has indicated that it intends to create centres of specialized care to address complex needs of some individuals seeking support. There will also be an investment in greater capacity for research to ensure that these centres and the rest of the sector benefit from the best knowledge available with respect to innovative ways of supporting people who have an intellectual disability.

"Specialized care" is a label applied to some individual supports that happen to be delivered by people with particular expertise in medical, psychiatric or other disciplines. Too often in the past, many of these supports have been delivered in ways that lead to labeling, studying and segregating people rather than aiming to support and include them.

Community Living Ontario believes that, investment in what is being called "specialized care" and enhanced research capacity would be beneficial to people being supported and to families and those providing support providing that these supports are delivered in community settings, based on individualized plans, do not label or congregate people and are aimed at providing people the support they need to participate effectively in the community. These initiatives must be designed in a fashion consistent with future directions, not past practices. To this extent, they should be thought of no differently than other supports that a person needs to live a healthy and productive life in community. The only difference is the particular expertise of those delivering the support. They should not be conceived of or created as centre or building-based options. They should serve to embed people in their communities and families. Consistent with recommendations of many participants in the forum on specialized care held October 19, 2004, such individual supports should be designed to first enhance the capacity of community supports. These options must also be available widely throughout the province, designed to respond to people in their home community, not based in a few locations to which people are forced to travel. Of course, consideration must never be given to reusing the existing 3 institutions as a base for these centres (as proposed by the union representing workers in these facilities); such a consideration would be exceedingly regressive and would not be tolerated.

Recommendation # 8 – Specialized care services and research initiatives developed as part of the transformation process must be based in and focused on building community capacity to support individuals who have an intellectual disability and assisting the

individual to develop the skills and relationship necessary to participate in the community despite their disability.

#### **Strategic Opportunities**

Two recent government announcements provide an opportunity for advancing some of the recommendations contained in this document. The first is the MCSS announcement of the plan to close institutions by 2009. The closure initiative will provide an opportunity to implement recommendations in the Community Living proposal. Planning processes for those leaving the facilities should be carried out in a fashion described in this document. Planning should aim first at connecting people to communities and building on community capacity rather than focusing strictly on program approaches - "placement."

The closure will also provide an influx of money to the community side of Developmental Services. While Community Living Ontario maintains its position that the money that is currently being used to support people in the institutions should follow them to the community, we should ensure that the expenditure of these resources is not automatically directed into traditional support options but is planned for and allocated in accordance with individual plans created for each person and that these individual plans work to maximize the capacity of families and communities in supporting and including these individuals, while providing the support that they need.

The Ministry has allocated \$70 million for capital resources to assist people leaving the institutions. It will be highly inappropriate if these funds are merely directed to the creation multi-bed residences; a move that would build more program based options. Such an approach would be directly contradictory to the principles that can produce real "transformation". Community Living Ontario recommends that these funds be directed into a "transformation fund" that can be used to pay for innovative residential and other support options consistent with individual plans of those leaving the facilities. Recommendation for use of these funds, or control of the funds themselves should be put in the hands of a community authority that can use them as a catalyst for innovative change consistent with the directions outlined in this proposal. Such a fund has been created in British Columbia as part of that province's transformation process and has provided a vital element in enhancing the capacity of the community to develop creative options for people.

Recommendation #9 – Planning for individuals leaving the institutions should be individualized and should aim to assist individuals to connect to family and community resources.

Placement in traditional service programs should not be the driving principle or objective for the closures.

Recommendation #10 – The \$70 million capital fund identified for providing residential options for people leaving the institutions should be established as a transformation fund. This fund should be directed or operated by a community authority charged with evolving creative alternatives for people leaving the institutions.

This recommendation would assist the sector by providing a vehicle for developing creative options in support of the transformation process.

The second recent government announcement that should be considered is the announcement on November 25 by the Minister of Children and Youth regarding changes to early childhood education. The announcement called for a number of initiatives including the establishment of a childcare/education component for the half day that children in Junior and Senior Kindergarten are not in classes; and the eventual provision of childcare services to all children from age 2 and a half. The announcement also called for the creation of a college for early childhood educators.

Recommendation #11 – That the government work to ensure that the proposed College of Early Childhood Educators includes within its principles a commitment for the full inclusion of all children in all early childhood centres, including children who have an intellectual disability; and that the expansions to child care announced on November 25<sup>th</sup> by the Minister of Children and Youth adheres to this principle.

This recommendation will help to ensure that all children who have an intellectual disability begin their life in the community as a fully included citizen.