

Report on

# **Consultations Regarding the Transformation of Developmental Services**

Prepared for

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Minister of Community and Social Services**

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# Introduction

Since the election of the Liberal government in 2003 there have been a number of initiatives undertaken by the Ministry of Community and Social Services (MCSS) aimed at transforming the services and delivery in the developmental services sector to create a fair, accessible and sustainable system for those living with a developmental disability and their families.

The Liberal government has boosted its spending in the developmental services sector to \$1.25 billion annually including an increase of almost \$59 million in annual funding to help families better support their loved ones with daily living activities. As well, the ministry is investing almost \$192 million in capital and operating funding to strengthen community-based services for enhancements in developmental services and community infrastructure and \$122 million for additional community services. Agencies are also strengthening staffing and continuing to ensure the safe operation of community homes as a result of this additional funding.

- In September 2004 the Liberal government announced its intention to improve support for Ontarians with developmental disabilities and committed almost \$70 million to create new residential options for adults with developmental disabilities who will be moving into the community from institutions.
- In January 2005 the ministry announced the launch of an innovative program using video conferencing technology to enhance access to specialized clinical services. The program is aimed at adults with developmental disabilities living in Northern Ontario, and allows them access to clinical resources without the challenge of extensive travel to cities where such services are normally delivered.
- A strategy to strengthen specialized care for adults living with a developmental disability

was announced in May 2005, followed by the launch of a project to test the effectiveness of new technologies to protect vulnerable people who are at risk of wandering.

- The Minister of Community and Social Services has initiated a process to consult and work with a broad range of individuals, families and community agencies to create the transformation plan for developmental services. The vision of full inclusion of Ontarians with a developmental disability in all aspects of society and finding ways to strengthen the families' capacity to provide care at home continue to be primary goals during the ongoing discussions regarding the transformation agenda for developmental services.

Over the past year the Liberal government has begun the transformation of developmental services in Ontario by enhancing supports that address the needs of people with a developmental disability living in the community and the community agencies that support them. Enhancements include additional funding for the Special Services at Home program that helps families support family members, and the Passport program that helps young adults with a developmental disability make the transition from school to a wide range of community activities or work.

As part of the review of the province's developmental services system, the following report summarizes what was heard at a series of consultations with parents and families of Ontarians with a developmental disability. The consultations were held to gain an understanding of relevant issues and concerns with respect to Ontario's developmental services system, and to ensure that the plan to transform the sector truly reflects the priorities of people with developmental disabilities and their families. The issues raised and recommended actions that follow in this report will help to provide a long-term blueprint for developmental services in Ontario; one that is focused on achieving the best possible results for Ontarians with a developmental disability.

# Historical Perspective

The province of Ontario has provided services to people with developmental disabilities for over a century. Ontario's developmental services system has changed greatly over this time, with the most significant shift being from provincially operated, institution-based services to community-based services that promote greater social inclusion, independence and choice for individuals.

In the 1800s it was widely accepted that people with disabilities should be moved to the periphery of society. At the time, distinctions between physical and mental illness were vague, as were those between disease and disability. As society accepted the idea of separating people with disabilities from society, many people were placed in institutions without regard to their particular condition or circumstance. Ontario's first institution opened in Toronto in 1841. People with developmental disabilities were institutionalized along with people suffering from mental illness for more than 30 years until specialized institutions were opened in London and Orillia.

The growth of institutions in Ontario continued throughout the first half of the twentieth century. The move toward de-institutionalization was spear-headed largely by parents as society's fear of people with disabilities began to be recognized as unfounded. Those with physical disabilities were first to return to society followed by those with developmental disabilities and finally those with psychological disabilities.

In the 1960s the province of Ontario had 16 residential institutions for 6,000 developmentally disabled people and few community-based supports that would enable individuals with a developmental disability to live in their communities. Between 1975 and 1986 Ontario's network of community-based services grew rapidly, including a number of programs that promoted independent living within the community. The number of people served in the community-based system grew from approximately

4,600 to more than 25,000. During that same 11-year period, annual spending on community-based services increased from \$10 million to \$181 million; five provincially operated residential institutions were closed and several others were reduced in size as communities, families and the provincial government helped hundreds of people successfully reintegrate into the community.

In 1987 the Ontario government committed to closing the province's remaining facilities within 25 years - a commitment that has been supported by successive governments since then. Between 1987 and 2004 Ontario closed another six facilities, bringing the number of residents who made the transition to community life to more than 6,000.

# Ontario's Developmental Services System Today

Today, only three of the province's original 16 residential institutions for adults with a developmental disability remain, serving approximately 1,000 residents: Huronia Regional Centre in Orillia, Rideau Regional Centre in Smiths Falls and Southwestern Regional Centre in Chatham-Kent.

The Ontario government now spends more than \$1 billion a year on community-based services for people with a developmental disability. These services provide financial and social supports to approximately 40,000 adults, primarily through community-based organizations. The range of services includes:

- Community supports to help individuals participate in community life, such as a broad range of day programs, speech and language therapy, counseling and behaviour management, supports to help individuals with the transition from school to community-based activities, other day programs and employment supports.
- Residential services including group living situations, individual living supports and the Familyhome program.
- The Special Services at Home program that provides funding directly to individuals/families who are not living in ministry-funded residential accommodations.

Ontario's positive experience with integrating people with developmental disabilities into community life continues to drive changes in the way services for these people and their families are shaped. For example, children with a developmental disability now grow up with their peers in their communities and schools, and families have more supports and services with which to help their children and family members live more enriched, independent lives closer to home.

By spring 2009 Ontario will have completed the move from an institution-based service system for adults with a developmental disability to a community-based system. By that time, an entire generation of Ontarians with developmental disabilities will have grown up in an increasingly inclusive society. As their support needs and service expectations continue to evolve, the people who provide those supports and services - families, communities and government - must find a way to respond so that the developmental services system is strong, forward-looking and sustainable for the future.

# Community Consultations

Over a six month period in 2005, parents and their children (often of adult age) were invited to meet with myself and staff from the appropriate Ministry of Community and Social Services regional office. Each office was asked to invite a cross-section of parents and caregivers to share their perspectives on relevant issues. Local MPPs were asked to invite constituent families who had been in contact with their office to express dissatisfaction or frustration with the current system. In addition, a significant number of individuals provided input through telephone calls and e-mails.

Consultations with parents, families and developmentally disabled individuals were held across Ontario in the following communities:

- Barrie
- Chatham
- Hamilton
- London
- Mississauga
- Oshawa
- Ottawa (English and French)
- Peterborough
- Sudbury
- Thunder Bay
- Trenton
- Windsor

Consultations were also held with various Community Living Ontario organizations, as well as other stakeholders from the developmental services sector including:

- Adult Protective Services Workers Conference, Hockley Highlands
- Bellwood Centre for Community Living, Queen's Park
- Brockville Community Involvement
- Coalition for Families and Care Givers of Developmentally Disabled Children, Queen's Park

- Community Care of South Hastings, Belleville
- Community Living Kingston
- Community Living London
- Community Living Ontario
- Community Living Picton
- Community Living Toronto
- Community Visions and Networking, Belleville
- Day of AccessAbility, Ottawa
- Developmental Services Joint Partnership Table Steering Committee, Toronto
- Developmental Services Policy Forum, Toronto
- Developmental Services Transformation Forum, Queen's Park
- Durham Family Respite, Ajax
- Families for a Secure Future, Queen's Park
- Families from Regional Institutions, Queen's Park
- Family Services Ontario, Niagara Falls
- LiveWorkPlay, Ottawa
- "Living Life Large" Support Group, Trenton
- Mental Health Support Network, Belleville
- Mississauga Opportunities 21, Mississauga
- Muskoka Family Networks, Barrie
- Muskoka Family Networks, Bracebridge
- Ontario Rehabilitation Work and Community Conference
- Pathways to Independence, Belleville
- Peel Behavioural Services, Mississauga Community Consultations
- People First Ontario, Mississauga
- Plainfield Community Homes
- Prince Edward Child Care Services, Picton
- Quinte Family Support Network
- REENA, Queen's Park
- Toronto Community Care Access Centres

Consultations were designed as small group meetings to ensure that all present would have the opportunity to participate in the discussions; each consultation included between 10 and 20 people. Over 200 individuals were involved individually or in small groups at various consultations. Without exception, the sessions were wellattended, with families expressing appreciation for the opportunity to be included in the consultative process.



# Issues and Recommendations

While many topics were covered during the community consultations, the following represents a summary of the most significant issues and concerns raised, and recommendations for consideration.

## A. Fair and Equitable Access to Adequate Community Supports

The Ministry of Community and Social Services funds a variety of services and supports to people of all ages with developmental disabilities and their families, primarily through a network of community-based, boardoperated and non-profit transfer payment agencies. Services funded by MCSS and delivered through community agencies include:

- In-home respite
- Out-of-home respite
- Specialized community supports to assist individuals with developmental disabilities to remain in the community
- Community living supports and residential services which include supports to assist individuals to live in the community, 24-hour group living situations and other living arrangements.

The Special Services at Home (SSAH) program helps individuals with developmental disabilities to live at home with their families by providing funding on a time-limited basis to address individual needs. With this funding, families can purchase supports and services which they could not normally provide themselves and are not available elsewhere in the community. Each family has a unique set of circumstances and goals. Accordingly, SSAH funding is tailored and may be provided for the following:

- Personal Development and Growth - This could include helping a person acquire new skills and abilities, such as improving communications skills or supporting a person as he or she undertakes more of the activities associated with daily living.

- Family Relief and Support - Families may have additional responsibilities in caring for a family member with a disability. SSAH provides funding for respite or parent relief and related supports. While the person with a disability will likely benefit directly, the overall goal is to help the family meet their identified needs.

During the community consultations it became clear that, while the provincial government provides a wide variety of supports and funding programs, people currently face a labyrinth when trying to find services, and many families have difficulty navigating the system to access the required supports based on their unique set of needs. There is currently no single point of access where individuals and their families can obtain support and services. As a result, there is a lack of consistency across the province with respect to key functions such as needs assessment, eligibility determination, referrals, resource allocation, service prioritization and information collection and sharing. The development of single points of access within communities should be considered as a starting point to ensure fair and equitable access to community supports for individuals with a developmental disability.

The issue of equity of supports, or rather the lack of equity, was most glaring at all of the consultations. Some of the families that attended receive substantial funding, while other parents asked 'What is Special Services at Home?' Clearly, there is a lack of information available to parents in some areas, while others enjoy the benefits of community agencies that encourage and assist them in seeking supports. A first step to overcoming the disparity is to ensure that every eligible citizen is informed of the programs and associated funding currently available in Ontario. There also appears to be a more difficult aspect to the equity issue - parents who are well-educated and articulate appear to have a much greater chance of obtaining funding or services for their family members than those parents without the skills required to effectively advocate for their child.

## Recommendations:

1. Review provincial access mechanisms, including the Community Care Access Centre model, to ensure individuals with developmental disabilities and their families can obtain support and services they need.
2. Develop a process involving the Ministries of Community and Social Services, Education, and Health and Long-Term Care to provide all parents of a child identified with special needs with an information package regarding available government programs.
3. Implement a new funding model; develop a funding formula that ensures funding allocations are based on need, within available resources.

## B. Families' Life-stage Needs

In the context of individuals with a developmental disability, families can be divided into three groups with distinct needs. The groups comprise:

- i Families with children who attend school
- ii Families with children over age 21
- iii Older families requiring future life planning

Although it is obvious that parents and families will move from one group to another as their children age, each group currently has unique needs which will be addressed separately in this report.

### Families with Children in School

The Ministry of Education is responsible for ensuring that all exceptional children in Ontario have available to them appropriate special education programs and services without payment of fees. However, even when attending school, the provision of care for a child with a developmental disability may require families to be available 24 hours a day, 365 days a year. Caring for an individual with a developmental disability can be exhausting, placing unreasonable strain on relationships within families.

These families clearly require some relief to allow for their own energies to be renewed and/or to devote some quality time to other children within the family, although this presents both logistical and financial challenges.

**Infrastructure support delivered through the community that supports both the individual and the family such as respite care is pivotal in alleviating the stress experienced by caregivers. Recent international qualitative research demonstrated that mothers of learning disabled children reported such social support provided personal significance to them in the quality of their life including the relationship with their child and across other areas of their life.**

Hartrey L, Well JS. 2003.

The meaning of respite care to mothers of children with learning disabilities: Two Irish case studies. *Journal of Psychiatric and Mental Health Nursing* 10[3], 335-342.

Parents of children with developmental disabilities noted that, while they currently receive funding for Special Services at Home, the funding is often inadequate. Many families are faced with the challenge of finding an appropriate relief caregiver, and given their child's unique needs they require a trained caregiver as opposed to someone able to provide general child care. Parents reported that even when they are successful in finding someone capable of providing care for their loved one, the funding provided is often insufficient to cover the caregiver's expected remuneration. Parents or guardians are forced to pay the difference and simply run out of money, and thus relief, part way through the year. In addition, it was clear that families employing relief caregivers tend to experience substantial turnover, as caregivers move to full-time jobs with benefits as

soon as possible. The subsequent change in care providers is often not in the best interests of the child or their family. The lack of qualified relief caregivers is particularly frustrating to families who have other children or relatives who are able and willing to provide care. There are many advantages to family care-giving, as relatives know the child well, and the child is more likely to be comfortable with the family caregiver. However, current regulations require Special Services at Home funding to be used for non-related caregivers and do not include provisions for structured family care-giving.

#### **Recommendations:**

4. Improve options available for family relief and support.
  - Review the adequacy of funding available for relief.
  - Encourage local agencies to establish regional 'pools' of qualified caregivers.
  - Amend current SSAH regulations to broaden the definition of suitable relief caregivers.

#### **Families with Children Over 21 Years of Age**

The needs of parents whose children are 21 years of age or over are very complex. Without exception, parents expressed the need for their children to have access to and take part in meaningful daily activities. Suggestions included dedicated work environments, paying jobs and day programs offered through community agencies. While many parents understand that their child may not be able to be gainfully employed, there are opportunities for individuals with developmental disabilities to volunteer for organizations or for commercial enterprises. A major barrier is the unwillingness of the insurers of these organizations to insure developmentally handicapped persons while at the placement. Nevertheless, all parents agreed that their first choice for their child would be day

programs that provide enriching activities similar to those currently available in school. With few exceptions, parents believe their children can and need to learn, and that without mental stimulation they will begin to lose some of their acquired skills and knowledge. The vast majority of people in our society are able to access various forms of education throughout their lives, such as night courses, certificate programs and post-secondary education; the same type of access is not readily available for people with special needs.

**Recent research has stressed the importance of person-centered planning for individuals accessing both paid and non-paid services for support. The overriding goal of this approach is to allow individuals and their families to make decisions and freely choose what services they require to meet their needs and achieve goals as defined by the individual.**

National Center on Secondary  
Education and Transition.  
Person-centered planning: A tool for transition.  
Parent Brief. 2004.

There was a strong sense that parents value the programs currently offered by agencies in the developmental services sector and want such programs to remain viable. However, in a number of areas parents expressed concern and dissatisfaction regarding access to provincially funded programs because the programs are available only for clients who have a residential placement with the agency delivering the program. While agencies would be amenable to offering programs for all individuals, they are often forced to restrict access due to funding limitations. This leaves individuals living at home without access to provincially funded programs.

Parents made their beliefs clear - programs should be accessible to all Ontarians with developmental disabilities. There was also clear consensus that parents want access to services from 9 a.m. to 3 p.m., similar to those available through the school system.

One of the real challenges for parents and caregivers tends to be one of transportation. In both urban and rural settings, very few parents are in a position to drive their child to and from day programs; some suggested that, as the largest publicly funded transportation system in the province, school buses should continue to be available to them. In addition, there was a great deal of frustration expressed about mobility transit systems, including the lack of system availability in some areas, lack of system reliability, regulations that stipulate an attendant accompany the child, and requirements that do not allow advance scheduling meaning that parents must book trips each day.

### Recommendations:

5. Determine the feasibility of obtaining a 'blanket' insurance policy covering developmentally disabled individuals taking part in volunteer placements.
6. Undertake a review to determine ways to provide an education component throughout life for people with special needs.
7. Improve access to transportation.
  - Encourage or require municipalities to establish or enhance mobility transit systems using a portion of provincial gas tax transfer payments.
  - Determine the feasibility of using public school buses for transportation to day programs through discussions with representatives of the Ministry of Education and the provincial public and separate school associations.

### Families Requiring Future Life Planning

There are ever-increasing numbers of parents and siblings in this province who will shortly be unable to provide the high level of care required by their loved one with a developmental disability. For these families, their constant concern is the well-being of their child or sibling when they pass away. It is

clearly very important to these families that their loved one not end up sleeping on the street, but instead be placed in a safe and nurturing environment, providing an atmosphere as similar as possible to what they are now experiencing. Of equal importance, caregivers want assurance from the government now that their loved one will be taken care of in the future. The vast majority, however, made it clear that they want their family member to remain with them as long as possible, moving only when absolutely necessary. Some parents with significant financial resources indicated a desire to construct homes next to or as part of their residence so their child, with supports, could live independently. They requested that tax laws be amended to allow credits for the construction and operation of such facilities.

**The need for innovative planning and family centered or person centered directed care plans is required to ensure individuals with developmental disabilities have the services they need in the midst of long-term care issues, aging parents and access to adequate support services.**

Parish SL. 2005. A critical analysis of the emerging crisis in long-term care for people with developmental disabilities. *Social Work* 50(4):345-54.

When an individual with a developmental disability is ultimately required to transition from the home, parents presented preferences for all of the following, depending on their child's situation:

- Independent, supported living
- 'Kin-care', wherein individuals related to the individual provide a home
- Host families, wherein individuals live with a non-related family who replicates a 'family' environment and receives compensation
- Community group homes

Given the ever-increasing demands for community living combined with spaces required by residents leaving the institutions scheduled for closure, there is clearly a need for additional residential accommodations and/or a need to expand the types of residential options available. On a related point, a number of presenters at the consultations made a strong case for establishing care settings that deal specifically with one particular challenge, such as autism, fetal alcohol spectrum disorder and Down's Syndrome, or individuals experiencing Alzheimer's; experience has shown that individuals with these disabilities do best when living with others experiencing the same challenges.

Community agencies continue to provide superb service to individuals and families in spite of increasing financial challenges. It is clear that their greatest pressure point is staff salaries, which have not kept pace with comparable jobs in other sectors. Agencies are in serious need of additional base funding to ensure that quality service continues. At the same time, all agencies and community living associations must be encouraged to explore mechanisms that will focus expenditures on clients.

While community agencies work to enhance services to their clients, government may play a role in ensuring the delivery of quality programs through the implementation of minimum standards of care. Strict standards currently protect Ontario's seniors; individuals with a developmental disability are also vulnerable and need similar protective measures. For example, community group homes are operated either by community developmental services agencies on a not-for-profit basis, or by private for-profit operators. In most cases, the not-for-profit organizations were founded by parent groups. Clearly, both types of homes strive to provide quality care. Based on personal visits and input from the communities, it is apparent that most of these organizations operate in a very efficient manner. However, while licensing and standards are required for almost everything in our society, no formal requirements exist for operating a group home, or for the staff employed within. While a license itself is required, there are virtually no requirements as to

the experience, education or history of those involved. Currently, group homes for adults with a developmental disability are not licensed by the Ministry of Community and Social Services, but are subject to meeting regulatory standards as outlined in the Developmental Services Act and Regulations. Establishment of group homes for children with a developmental disability falls under the Child and Family Services Act and Regulations.

It is generally accepted by participants at the sessions that agencies in the developmental service sector deliver high quality programs. As the government moves forward with the transformation of the developmental service sector consideration must be given to developing a regulatory and legislative framework to ensure that clients are getting the services they require to improve their quality of life in the community. There is currently a lack of legislation regarding these operations.

### **Recommendations:**

8. Increase the number of available residential options.
  - Provide funding to create additional community living spaces.
  - Review and expand the types of residential spaces eligible for funding.
  - Explore the potential of provincial tax credits to facilitate the construction and availability of alternate residential spaces.
  - Explore the advantages and disadvantages of establishing specialized care settings to serve clients with a particular disability.
9. Encourage agencies in the developmental services sector to achieve operational and administrative efficiencies possible resulting from working cooperatively.
10. Develop a set of provincial standards to own/operate a regulated group home, and establish minimum qualifications for the staff of such organizations.

## C. Parental Responsibility

All parents attending the consultation sessions were asked about the balance of responsibility between themselves and the government to provide care for their child. With few exceptions, parents feel very strongly that the government has the same responsibility to individuals with developmental disabilities as it does towards seniors in long-term care.

Although governments have traditionally provided resources for programs, services and accommodation to assist families and individuals to support those with developmental disabilities, there is no current legislation that requires the government to assume the role of parent or caregiver in providing the range of services and supports that it currently does for the developmental services sector. Over the years, governments have been guided by social values of the time and the public's perception of moral obligation versus actual legal responsibility.

After caring for and financially contributing toward services for their children, parents believe it is the government's responsibility to contribute once children with developmental disabilities leave home. There also appears to be a perception by some parents that the government possesses unlimited funding for supports. Indeed, a significant number expressed the belief that 'we have cared for our children for years, saving the government millions, and now it's the government's turn to pay us back'.

Exceptions to this viewpoint included two parents who stated that rather than money from the government, or even social assistance for their child, they would prefer to receive tax credits for money currently being spent on their child's care, and to have legislation changed to allow them to freely bequeath assets to their children. Every participant expressed frustration with their inability to bequeath assets without causing their child's removal from the Ontario Disability Support Program (Ontarians with developmental disabilities are eligible for income and employment supports through the program). Parents found this particularly difficult to accept as they could leave any assets they wish to other children, or anyone else for that matter, but

leaving assets to a child with a developmental disability might be disadvantageous for the child. Parents acknowledged that there is currently a mechanism to bequeath assets to an outside trust to administer on behalf of their child, but they strongly believe that they should be able to choose a relative or friend to protect the best interest of their loved one.

There is an additional anomaly in the developmental services system, in that parents are encouraged to set aside funds for their child's post-secondary schooling, but no such mechanism exists for parents of individuals with a developmental disability who will require support for their lifetime. At the present time, any savings put aside in a child's name is treated as belonging to the child, and thus falls within the maximum allowable savings permitted according to Ontario Disability Support Program (ODSP) regulations. Additionally, funds received through ODSP cannot be invested, further constraining a family's ability to adequately plan for the future of individuals with developmental disabilities. The creation of a savings mechanism with some federal government matching funds would provide both financial savings for the provincial government and peace-of-mind for parents.

Discussion at all consultations included concerns regarding the future sustainability of funding for developmentally disabled individuals. There was broad agreement that a compromise is ultimately required between the needs of Ontarians with developmental disabilities and their families, and the ability of governments to fund developmental services. To that end, there have been ongoing discussions between federal, provincial and territorial governments with regard to national disability income and support programs.

The goal of a National Disability Income Support Program would be to provide a nationally consistent adequate level of income to all people with severe and prolonged disabilities who are unable to work or who have limited capacity to work. Dedicated transfers from the federal government to provinces and territories would allow each region to prioritize

allocation of funding based on local needs. The goal of a Dedicated Transfer for Disability Supports would be to enhance the integration of persons with disabilities in Canadian society by increasing access to a range of goods and services that are essential for their active participation in daily living.

Based on decade of studies, there is strong support from the experts that there is a clear need for disability supports and income. For individuals living with a disability, a nationally consistent approach would clarify roles and responsibilities: the federal government would provide income support while provinces and territories would provide in-kind support programs and services. It would also ensure that support for individuals living with a disability is portable across the country and equitable for all Canadians.

**In 2003, the National Union of Public General Employees (NUPGE) in Canada called for a “national public system of disability support services and income support”. The NUPGE called for all levels of government to participate in the “social investment in individuals with disabilities, along with their families and communities.”**

The National Union of Public  
and Genreal Employees.  
Diability Rights an Integral Part of Our Union’s Agenda.  
National Union of Public General Employees.  
2003. 26-1-2006.

## Recommendations:

11. Improve families’ ability to plan for the future needs of individuals with developmental disabilities.
  - Continue to approve ODSP funding for all qualified individuals, regardless of family income or assets.
  - Amend current legislation to allow parents and/or siblings to bequeath assets to a trust administered by the individual or firm of their choice.
  - Allow ODSP recipients to allocate their spending for current and future needs (e.g. for example, allow contributions to RRSPs).
  - Hold consultations with the Federal Government with the purpose of establishing a Future Disability Trust Fund to permit parents to set aside funding for their child’s future needs.
12. Undertake a review of current funding options to determine what is reasonable and sustainable regarding the funding of individual needs for Ontarians with developmental disabilities.
13. In conjunction with all provinces and territories, exert pressure on the Federal Government to develop and implement a National Disability Income Support Program and Dedicated Transfer for Disability Supports.

## D. Ontario Disability Support Program

A significant number of parents indicated that they were not looking for a 'day program' for their child, but rather a real, income-producing job. Parents believe that the system should do everything possible to foster a greater sense of independence and provide opportunities for individuals with developmental disabilities to augment their income beyond social assistance funding.

The Ontario Disability Support Program is an Ontario government program designed to meet the unique needs of people with disabilities and their families who are in financial need, or who want to work and need support. During the consultations, the idea of a family means test as a component of eligibility was raised. Participants in the consultations voiced very strong opposition to the idea; they believe that funding received from ODSP belongs to the individual with the developmental disability, as opposed to the parents, and therefore a family means test would be inappropriate.

Participants also noted that individuals attempting to augment their income beyond ODSP funding face several disincentives. Earnings exemptions, whereby funding is 'clawed back' or reduced for ODSP participants once they earn a certain amount of paid income, act as disincentives to engage in paid work. Current regulations provide for a 75 per cent 'claw-back' for any earned income over \$165 per month; clearly the regulations are a very strong deterrent to seek employment. As of August 1, 2005 current earning exemptions for Ontario Works (Ontarians in temporary financial need receive financial and employment assistance through the program) have been replaced by a straight 50 per cent exemption rate. This means that no matter how much an individual earns, only half of the employment income will be deducted from Ontario Works payments. A similar change to earnings exemption rates for ODSP should be considered.

Another related and significant barrier to employment is the regulation that requires ODSP recipients to report gross rather than net income. ODSP participants tend to have above-average living

and employment costs which are not currently offset, nor deducted from gross income for reporting purposes. For example, individuals with a mobility challenge may well be able to undertake employment which involves driving their vehicle; however, under current requirements individuals cannot deduct employment-related expenses such as gasoline and depreciation. In this way ODSP participants may be disadvantaged through their efforts to participate in the labour force.

On the other hand, those who might choose to exit the ODSP system also lose access to important drug benefits. For the vast majority of jobs available to persons with developmental disabilities, the reality is that employers do not provide medical benefits; at the same time, it is very likely that such individuals have above-average medical expenses. The loss of benefits clearly presents a barrier to employment, thus keeping individuals on ODSP and incurring taxpayer expenses that could be avoided.

For those individuals who do choose to exit the system for paid employment, the fear exists that if their employment does not prove to be long-term, they may have to wait months to get reinstated in the ODSP system. While the previous government established a process for 'rapid re-entry', anecdotal evidence indicates that the process does not always work effectively.

It should be the philosophy of our society that whenever possible, an individual is moved from ODSP to paid employment. Often, a disability which prevents an individual from doing a particular type of work may not be a problem for an alternate type of employment. In many cases, if not most, the transition will require some postsecondary education. In the case of ODSP recipients, government education loans are currently considered to be income, and therefore alter participants' eligibility status for ODSP benefits. Instead of providing supports for individuals with developmental disabilities to move toward independence and a full life within their communities, many ODSP regulations encourage continued dependence.



## Recommendations:

14. Consider changes to the calculation of earnings exemptions to encourage labour force participation.
  - Substantially increase the amount of earned monthly income allowed prior to any ‘claw-back’ or implement a straight 50 per cent exemption rate.
  - Calculate earnings exemptions based on the net (vs. gross) benefit to ODSP participants.
15. Change the rules to ensure that OSAP loans, to the value of tuition, books and supplies, not be considered income for recipients upgrading their education.
16. Provide permanent medical benefits for individuals with developmental disabilities who leave ODSP to seek employment; allow individuals to retain their drug card regardless of income, or until their income reaches a certain level.
17. Take steps to ensure that individuals leaving the ODSP system for paid work are immediately reinstated if their job terminates for whatever reason.

## E. Closure of the Institutions

Some of the participants in the consultation sessions were parents or family members of an individual currently living in one of the three remaining residential institutions scheduled for closure by 2009. In the majority of cases, families placed their children in the institution as long as 60 years ago, with the promise that they would be looked after forever. Without exception, families noted that the institutions are considered ‘home’, and staff members are considered ‘family’; any disruption to the current arrangements could be most unsettling for residents. While the majority of families recognize that previous closures ultimately resulted in excellent service for former residents,

many believe their family members are of a higher need, and urge that the institutions remain open. In addition, the current facilities have the advantage of readily available medical care for residents, particularly those considered ‘medically fragile’; families are particularly concerned for the future of these individuals.

Relatives of current residents continue to believe that energies should be devoted to persuading the government to reverse the decision to close the remaining institutions. In many cases, the position of the families can be attributed to the lack of current information available to them, and may be a reaction to unfounded rumours relating to the impending closures.

## Recommendations:

18. Assist residents and their families with the transition to community care.
  - Pair ‘planners’ with families of developmentally disabled individuals to develop individualized transition plans for each resident, and ensure that residents are placed in the most appropriate setting.
19. Give special consideration to those deemed ‘medically fragile’.
  - Consider the provision of specialized medical services where necessary, noting that in some cases the provision of such services may require specialized settings.
20. Improve communication regarding institution closures.
  - Undertake a targeted communications initiative to provide timely and accurate information with respect to the transition of residents.

## F. Future Directions

With respect to the developmental services sector, the major challenge facing the government will be the increased demands on funding created by the maturing of the baby-boomer generation and the improved longevity of individuals with developmental disabilities. In addition, equity requires that funding be available to all individuals and families faced with such challenges, based on the degree of need.

Quite simply, future funding may not be available to meet the utmost needs of every individual, but should provide a solid base for daily living. This can best be attained by providing 'individualized funding' for each developmentally handicapped Ontarian, with that funding flowing directly to the individual and/or family, or to the community resources providing residential and support services.

**Social consensus since the mid-60s has suggested that individuals with developmental disabilities should be at home with families and in the community with their friends and peers. Research has demonstrated that individuals who move from an institutional setting to community living experience increased quality of life. Furthermore, the intersection of resources from both the community and institution were associated with positive outcomes.**

Cooper B. 2000. The long-term effects of relocation on people with an intellectual disability: quality of life, behavior, and environment. *Research on Social Work Practice* 10(2):195:208

### Recommendations:

21. Create and manage a comprehensive information database containing information on existing clients, resources, contacts and future needs (e.g., number of individuals, projected total funding available).
22. Establish criteria for determining the level of individualized funding available for each Ontarian with a developmental disability.

# Conclusion

The consultations held earlier this year with developmentally disabled Ontarians and their families represented opportunities for the government to gain an understanding of relevant issues and concerns with respect to Ontario's developmental services system, and to ensure that the plan to transform the sector truly reflects the priorities of people with developmental disabilities and their families. In this regard, I am hopeful that the foregoing report accurately represents the points of view of those individuals and families who gave their time, shared their experiences and expressed their ideas through the consultative process.

Many of the recommendations in this report, if implemented, will continue the transformation of the developmental services system, improving the lives of individuals with a developmental disability and their families. The recommendations begin to address issues of fair and equitable access to community supports for all Ontarians with developmental disabilities, and acknowledge the reality that individuals and their families have different needs, goals and plans to achieve their full potential. We need to continue to support these families and their communities to ensure that individuals with developmental disabilities are served through a strong, forward-looking and sustainable sector.

Finally, on a personal note I wish to thank the staff in various regional ministry offices for their assistance with the consultations. The vast majority of workers in the developmental services sector are engaged in more than just a job; they are caring people living their passion. I also wish to thank the families who were instrumental in the community consultations. I must mention how impressed I was with the absolute and total commitment of these individuals to their children. Many of them truly deserve to be called 'heroes'. And most importantly, I would like to acknowledge the privilege I've had of meeting many, many individuals with developmental disabilities; their sincerity and innocence serves as a model for all of our society.