



Community Living
Ontario

Intégration communautaire
Ontario

Report of Community Living Ontario Regional Federation Days

***Regional Perspectives on the
Joint Partnership Table Discussion Paper
Transforming Services in Ontario for People Who Have a
Developmental Disability***

November, 2004

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Introduction

During October and November of 2004, Community Living Ontario held 5 Federation Day forums in different parts of the province. The purpose of these events was to gather the ideas and opinions of Community Living members, and others about the Preliminary Discussion Paper – *Transforming Services in Ontario for People who have a Developmental Disability*. The discussion paper, prepared by the Joint Developmental Services Sector Partnership Table, was written to raise questions that are intended to help people share their own ideas about how future supports and services for people who have an intellectual disability should be provided.

Community Living Federation Days were held in the following communities:

Timmins – October 23
Dryden – November 6
Kingston – November 6
Richmond Hill – November 13
London – November 13

Each event consisted of 3 main elements: a presentation of Community Living Ontario's Citizenship Agenda; an overview of the Preliminary Discussion Paper and planned government consultation process; and, discussion of the Preliminary Discussion Paper.

This report provides an overview of the 5 events including: highlights of Community Living Ontario's Citizenship Agenda and the key messages from that presentation; and, the specific points of discussion and recommendations from each of the 5 regions.

Community Living Ontario Citizenship Agenda

Before 1974, the provision of support to people who had an intellectual disability was seen as a health issue. Supports focused on things such as prevention, treatment, and cure. Most supports were provided through the Ministry of Health. Available services included large institutions and a growing number of community-based programs operated by not-for-profit organizations.

In the 1970's the Canadian government established the Canada Assistance Plan (CAP) as a mechanism for sharing the cost of social programs with the provinces. In 1974, The Ontario Ministry of Community and Social Services took over responsibility for funding supports and services to people who had an intellectual disability. Supports and services were redefined as "welfare programs" and the focus became ensuring protection and security for society's "most vulnerable" members.

The focus and expectations of people who have an intellectual disability have again shifted. Today the focus is on removal of barriers and providing supports that enable citizens with disabilities to take their place in society.

The Welfare State

The evolution of disability supports has been strongly influenced by the welfare model of the past 30 years. In 1987, the Ministry of Community and Social Services released a plan to guide the evolution of supports and services for people who have an intellectual disability, *Challenges and Opportunities*. This plan signaled the end of the health approach to supporting people by establishing a plan to close all of the remaining large institutions in the province. The plan also built on the welfare approach from the 1970s by calling for a comprehensive set of services that would provide people places to live, work and participate in the community.

So what is wrong with the welfare model? The welfare model, as described in documents such as *Challenges and Opportunities* envisioned the creation of a “Community-within-the-community” for people who have an intellectual disability; or, an “Institution without walls”. The comprehensive system of services envisioned at that time was designed to shelter and protect people. Living a safe life within community, is not a bad thing, but the approaches that have been used, too often have a negative side effect. Our approaches have often lead to individuals becoming dependent on programs and services rather than on community.

By providing people a safe and sheltered alternative to the real community, people failed to develop the skills, relationships and resources necessary to increase self-reliance and grow as contributing members of the community. “Special” schools and classes, sheltered workshops, etc., separate and protect people from society. People with disabilities can and should have a role in society. People only learn to live in the real world when they actually experience the real thing, not a simulation.

Self-advocates increasingly view organized services as a barrier to the community and are demanding support to participate in the real world. Citizens with disabilities need and deserve to be included in regular society.

How Should We Approach Change?

The aging generation of people who have an intellectual disability experienced segregation, institutionalization, discrimination and marginalization. These individuals were never embedded in the community and have grown to rely on the programs and structures that have been created for them. Planning for the future must recognize the legacy of our past decisions. We owe these individuals the shelter and protection that they have come to depend on. Of course we must continue to evolve these programs to ensure that people receiving support have increasing opportunities to develop connections and relationships within the community. The reality is, however, that these services will be needed for some time to come; in some cases, throughout the remaining life of those being supported. This means that, in building the new platform for delivering future supports, we cannot cannibalize the sheltering, protective

residences and day programs the aging generation still requires. We are obliged to maintain a traditional services system for the generation that has come to rely on it. Having said this, we must also recognize that this system, too, will continue to evolve and will require some investment of resources to do so.

For the new generation, however, our approaches must be very different. First we must recognize that inclusion is a starting line – not a finish line. The challenge will be to “**embed**” the next generation in the community so that they develop reliance’s on individual relationships and community resources.

Webster’s seventh edition offers the following definition:

embed 1 a : to enclose closely in a matrix b : to make something an integral part of 2 : to surround closely.

A Starting Point – a Citizenship Approach

One good starting point for considering the changes that might have to be made to better support people who have an intellectual disability is the 1998 *In Unison* agreement. This agreement, struck between the Federal/Provincial/Territorial governments, describes a new approach to disability issues in Canada. *In Unison* acknowledges the citizenship rights of people with disabilities, and acknowledges government’s responsibility to uphold those rights through funded supports.

An orientation that starts with citizenship instead of welfare will enable a different future path of evolution. It will enable the community to include people with disabilities, and, simultaneously, will enable the person to participate in spite of his disability.

Citizenship will have the best chance at flourishing when:

- People have a sense of belonging and attachment to the community;
- People with disabilities participate in the community;
- Human rights are protected;
- Individuals, governments, and diverse communities partner to remove barriers and provide needed supports;
- Communities take responsibility to support all members of the community.

A plan for how to better support people who have an intellectual disability must invest in strategies aimed at supporting these elements. The previous generation’s welfare based strategies have taken us as far as they can. When considering a new policy direction for the future, we must ask ourselves “What is our Core Business?” Are we here to operate welfare programs or are we here to facilitate citizenship?

The Ministry of Community and Social Services has committed to establishing a plan for transforming the developmental services system. Transformation will not occur if we focus on issues of service provision. Transformation will occur if we focus on our true

business of facilitating citizenship. Such a transformation must take place, not within the Developmental Services sector, but in the community as a whole.

Key Messages Emerging from the Community Living Ontario Citizenship Agenda

Transformation should be based on the following assumptions:

- Strategies for change must be focused first on developing community capacity to remove barriers and provide supports necessary to ensure the participation of citizens who have disabilities. Strategies must recognize that the community is the vehicle for change.
- Individuals and families are the decision makers. This applies not only to decisions about personal life plans, but to planning for social change where individuals and families need to play an integral roll in government policy development.
- As long as we continue to segregate children in their early years within the education system, the government will face demands for specialized, segregated services for adults leaving the school system. We must stop creating dependency on government services and focus on embedding people within the community. This begins with an inclusive education system and inclusive early-childhood supports.
- For a very large number of people who have been segregated in their early years and supported within traditional services as adults, the system has in many cases created a dependency on these services and supports. It will be difficult and sometimes impossible to change expectations. This means that many people will require specialized segregated services throughout their life.
- To ensure transformation there must be strategies that stimulate, encourage and support innovation at the community level.
- While there is commitment and interest in moving quickly with respect to this planning initiative, true transformation will take time. The planning process must not jump too quickly to final conclusions. As was done in the last Developmental Services planning initiative *Challenges and Opportunities*, the plan should outline key strategic commitments of the government including timelines that allow for research, evolution of thinking, policy development and implementation.

Recommendations for Change

Following are the comments and recommendations pertaining to the Preliminary Discussion Paper from each of the 5 forums.

Report from forum held in Timmins – October 23, 2004

While the forum held in Timmins reviewed the 7 questions contained in the Preliminary Discussion Paper, responses focused on the paper as a whole. While discussion covered issues addressed by the 7 questions, participants did not limit discussion to only these issues. Following is an overview of the key points of discussion and recommendations.

The Change Process

Trust – participants wondered if they can trust the government at this time to follow through on the commitment to transform the way that people with an intellectual disability are supported. Individuals need assurances that the supports they need are going to be there to be available when they are needed to ensure continuity. People need to be sure that basic needs of health and security will be addressed. Participants identified that that reform must focus on ensuring excellent individualized planning that can address these issues.

A mechanism is needed to evaluate the transformation plan as it proceeds and to make adjustments as necessary. Evaluation of the transformation plan should focus on outcomes it achieves for people, not just dollars. Further, evaluation should focus on the measuring the outcomes that we are attempting to achieve for people today such as citizenship and community inclusion, not the ideas and strategies of the 1970s such as the availability of residential and day programs.

The Transformation planning process has so far been driven exclusively by representatives from southern Ontario. Representatives from the North must be included in all aspects of planning and evaluation of this transformation initiative. This representation from the north must include individuals who have an intellectual disability.

Individuals and Families as Decision Makers

The needs of individuals as identified through individual planning should influence government planning and the future directions of funding and supports. Approaches used must ensure that people with disabilities and their families are the decision makers. This applies to both individualized planning and planning for changes in

government policy and funding. When planning policy and funding directions, government should talk to individuals and families not just those who provide services and those that work for government.

Support for Children

Given recent advancements in pre and post-natal care, many children who in the past would have died as a result of the severity of their disability are surviving. This indicates a potential demographic increase in the number of individuals who will have an intellectual disability in the coming years. Despite the current needs and this expected increasing need for services to children who have an intellectual disability, the Transforming Services in Ontario discussion paper is almost silent with respect to children. Failing to effectively address the need to adequately support children with disabilities in this province is a serious concern and must be addressed as part of the transformation process.

Inclusion at a very young age would lead to better inclusion throughout life.

Changes are needed in the education system to ensure that children who have an intellectual disability are included from the beginning. Awareness is needed in education system to remove attitudinal barriers. There is a need for training for all teachers to provide them the information and tools they need to be able to ensure the inclusion of all children. The education system must work to facilitate greater peer support for students who have an intellectual disability and provide one-to-one support when needed.

Addressing Public Attitudes

Attitudes in society need to change to better include people. Strategies and investments must be considered to facilitate this change. Some of the strategies to consider for changing public attitude are:

- ensuring that there is good information available to the public about the role that people who have an intellectual disability can play in our society and what is needed to ensure their inclusion (i.e., newspapers - open houses)
- Sensitivity training for the public to make them more aware of people with disabilities.
- Help people to understand how to interact with people who have a disability. People need help, but do not need others to take over their life.

Employers need more information about what people with disabilities can do in the workforce. They also need to be provided with clarification about the kind of support that individuals require to be part of the work environment and how to provide accommodations. There is a need to develop strategies to make it a win-win for the employer and the person that is looking for work.

Bringing People Home From Institutions

Supports for people coming out of institutions must be in place – all of the money currently being used to support people in institutions must accompany people as they leave the institutions. We must consider how to use the institutional money to increase the capacity of the community to respond to the needs of individuals.

We must make sure that necessary services are available to support people in the community – how will we address the medical needs of people returning from institutions? At present 60 – 70 % of people in the north do not have access to a doctor. People rely on clinics that do not provide the continuity of care that people require. Northern communities have a shortage of some of the medical and other supports and services that people coming home from institutions will need – the capacity of these communities must be addressed.

There is a need for transparency with respect to the needs of people coming back to communities from institutions so that communities know clearly what will be needed to ensure appropriate supports are provided (full disclosure).

Some questioned whether we can we provide adequate attention to both a deinstitutionalization initiative and a planning process to transform supports and services? Given the current stresses that the system is dealing with today, can we do it all? Some felt that it would be wise to stabilize the community system before we address further deinstitutionalization.

Timely and Adequate Supports

Some participants identified the need for more life skills programs particularly at the high school level to assist student prepare for greater independence as adults. Providing this support earlier will result in people having a better quality of life and will lead to savings for the system in the long run.

Participants identified the need for support for people leaving the school system. There is little or no support available for people leaving school and by the time they get through waiting lists, skills have slipped. People that have been included during their time in school do not want segregated day programs but families need a safe place for their son or daughter to go once they are finished school.

We need to enhance access to post secondary education for people who have an intellectual disability. The requirement to pass the grade 10 literacy test to get into college creates a barrier that excludes many people who have an intellectual disability from attending college. There should be accommodations including different ways of taking the test to provide people a greater chance at success.

There needs to be greater portability of funding to allow people more flexibility with respect to where they receive supports and services.

There is a need for increased awareness and an increased focus on honouring cultural diversity with respect to the support that people receive.

Participants discussed how best to ensure that adequate staffing supports are available to meet people's needs. Some suggested that this could be addressed through a system of required staff ratios including a formula such as exists in other sectors. Others felt that the adequacy of support should be addressed individualized planning that identifies the needs of people and the unique ways of addressing these needs including the use of family and community resources to provide supports. There was broad agreement that, when needed, staff support should be adequate to meet individual needs. The measure of adequacy will be different from person to person. We do not always need to rely on paid staff.

Many participants commented that the funding available through the Ontario Disability Support Plan (ODSP) Income Support is not enough to live on. People need a livable income. People questioned why funding is different for people living in different environments and the fairness of this practice.

Ensuring Qualified Support

Participants identified the need for more training to ensure qualified staff followed by incentives for staff to remain in their position once hired.

Professional services are slowly disintegrating. It is difficult to attract and keep professionals (speech language in both languages, physiotherapy, etc.) Organizations are beginning to develop more partnerships to address this issue in order to provide a greater incentive to people being hired.

On-going training should be available to help people respond to changes over time in the way we support people who have an intellectual disability. There is a need to share learning – connection to research capacity in the universities. Community organizations do not currently receive funding to provide training. If such funding was available, services could ensure more qualified staff. To address training needs in the north, there should be access to more long-distance training such as Contact North Ontario Learns.

Report from forum held in Dryden – November 6, 2004

The session in Dryden started with an open discussion asking the participants about their perspectives and what needs to change to better support people who have an intellectual disability. Following is a summary of key points of discussion.

- Ensuring protection for people is a key element that must be considered in the plan.
- We must work together for safety in the community.
- We must ask ourselves what are peoples rights? Legal rights, political, or ethical rights? We must ensure that people have equal rights as with any other citizen – “I am Canadian!”
- Rights can conflict. Example: Children living with alternative families who are volunteers seen as contracting out work of the union.
- Citizenship – What do we do first? Proposed amendments to the Ontarians with Disabilities Act (ODA) are a good start.
- Negative vs. positive right. You have a right not to starve to death – who has the responsibility to provide? Right for a job is a positive example of a “right”. Rights need to be enabled – someone must provide resources.
- Are families being squeezed out as a resource for supporting an individual. There is a concern that families will get cut out of the loop. Emphasis on families as decision-makers seems to be a reaction to them being left out.
- People with disabilities have to go through hoops that seem to be based on an idea that the disability might go away.
- Education should be available as long as people want it.
- We set up barriers where none were before.
- “Transformation” needs to be broader. Partnership in transforming the social service system needs to involve other ministries, other levels of government.
- Persons in conflict with the law: in Atikokan, police recognize that special circumstances should be considered. Treating people all the same may not be equitable or fair given individual differences. We need to have some protections in place.

- Society determines the nature of the family and it changes over time. Different cultures have different norms. Being included means being in a particular community, and communities are not all the same. In a pluralistic society, which the North is, differences should be respected.
- There are both group and individual issues that need to be considered/balanced. Pluralistic society is at different levels, e.g. school system educates students from different cultural groups.
- Diversity must be respected - community / race / language, etc.
- Policy research – funding framework. Here it is November and no one has their funding for 2004-05. Government's financial commitment should be due on a fixed date, just as our submissions have to be in on a set date. Partnership?
- Increase ODSP 23% to make up what has been lost due to inflation over the past 11 years.
- Partnership table incomplete: Responsibility for rolling out a process. There will be other opportunities for input from all sectors.

Responses to Questions from the Preliminary Discussion Paper

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

Individuals who have an intellectual disability must be afforded the opportunity to visibly advocate for themselves and participate in all planning

Families must have a greater voice in decision making and must advocate for their family member with a disability. Families should work in partnership with all service providers if possible. If families are not afforded these opportunities they should become political ("power of the parent") to ensure services are being provided

All governments should ensure that communities are funded to provide accessibility to all services in the community. This will require a greater commitment on the part of the government including annualized dollars, new money for each new client. Monies should be attached to the individual not program.

Service providers are responsible to carry out programs that will address the goals of individuals and families

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

Government needs to be more knowledgeable about the needs of all areas as well as the unique needs of persons, e.g. family and children's services must work with the school system, which needs to be aware of the child's needs and supports. The School system then works with parents. All should work together as a whole group. Services and agencies need to work together rather than separately.

Specialized supports/services should be available in all regions. There should be more training for doctors, teachers, GPs, so we can identify when there will be needs for specialized supports

Parents need to be informed of their rights and those of their children. They need to recognize and speak about gaps.

There needs to be more engagement with society, business including an increase in funding for supported employment

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

Supported Independent Living (SIL) programs seem to work well. Life Sharing works well in Kenora (as well as family home sharing).

Planning must recognize that there are two groups: a) individuals who have a history with current method of service and don't want a great deal of change b) "younger" individuals who are now looking for different types of support.

Planning strategies must follow the principle "If it's working, don't change, simply to change."

Supports and services must be designed to fit the unique characteristics of each community, for example, native culture may have profound impact on certain communities. Government 'micro-management' does not work well. All communities differ, and all communities change over time. Planning approaches must allow flexibility.

Question #4 - How should a reasonable level of government funding for an individual be determined?

Participants believed that the question should address the resource needs of each community, as this will determine the level of resources.

- health care: unequal access issues

- education: is not always inclusive (some are). In communities where students grow up within a culture of inclusion, their expectations for support will likely be different as adults
- Southern Ontario does not give enough importance to Northern Ontario needs due to difference in resources available
- Travel: cost vary according to distances
- Cost of Living variations
- Flexibility re: disasters (e.g. job lay-offs) economic situations within each community
- Level Of Support test: Questionnaires insulting....needs to be more sensitive to actual needs and 'condition' of disability

Funding allocations must recognize issues related to aging: funding allocations must be flexible as needs change as people age.

Funding allocation must recognize the effect of unionized service providers as unions can affect means in which service providers can provide services/resources available.

Should degree of handicap affect the amount of funding provided? Group felt there presently wasn't a fair/suitable means of determining an allocation based on the degree of handicap that the person experiences.

Creation of a mechanism for allocating funding cannot be rushed it is complex and will need careful consideration.

Leave funding in the hands of the 'families'.

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

Question was not specifically addressed

Question #6 - What do you think are the priorities the government should address?

Part A:

Transformation should start at the beginning, and should be 'whole'. Whole system should be reviewed and not just the 'parts'. Some very good parts that currently exist, but they do not fit together as a system.

Recognize the individual person within the context of society

- investment should be early on, therefore there will be savings later on

- social cost benefits analysis should be one of the means of evaluation and determination

There should be 3 levels of support: a) mandated services (guaranteed basic services) b) negotiated and optional services and supports c) predetermined as not being funded e.g. vacations. This should be done individually with life-long funding, with the 3 r's the right time, the right level and the right amount.

Part B:

Be realistic in terms of process, and system evolution, taking into account the Northern allowance and factors.

Part C:

Everyone should work together for a better tomorrow.
We want to have all partners being equal.

Part D:

Participants asked, who are the experts on the Expert Policy forms? How many people are from the North? First Nations? Consumers?

Question #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?

Ontario Disability Support Program (ODSP) Income Support should be increased by 23% and provide support for transportation

A process should be developed to hold a meeting at the community levels in each community, to form a plan as to how community capacity can be built.

There should be a meeting of Social Services ministers with their Federal counterparts to come up with plan to implement the In-Union agreement.

Turf wars need to stop between Ministries and they must find ways to work together to ensure that needs are met.

There must be northern representatives at all tables – funding from the Ministry needs to reflect unique Northern needs (all of the North) e.g. travel

Plans must address the need for public education. Communities need better information about the issues facing people who have an intellectual disabilities and the

support that they need and receive to live in the community. e.g. posters. Also include education for doctors, teachers, etc.

Inclusive education non-negotiable. Recognition that education is life-long and funding must reflect that.

Plans that the Ministry develop must be adequately funding and must including deadlines/commitments that are responded to in a in timely manner.

Community profiles should be developed to identify the unique issues facing each community as it works to support people who have an intellectual disability. Each community profile should prioritize areas that need funding.

All agencies be mandated to cooperate in an initiative to share information and coordinate services. This initiative should be done across sectors, not just in Developmental Services.

Other key issues to be Addressed

- All services in the community should be universally available
- Maintain and create diverse options for services
- More housing
- More cooperation between agencies most specifically schools and service agencies
- Access to resources is not available in communities
- Public awareness
- Stream lining of supports
- Ministry accountability for deadlines
- Qualified and education staff
- Individual community needs
- More community services
- More flexibility
- More supports in the schools
- Ministry accountability - Meeting deadlines and providing funding they say they are going to provide
- Have a community Profile – pick out top 3 areas that require funding
- More Money
- Education system – inclusion and training essential
- Elimination of silos
- Knowledge of unique geographical needs of communities to inform planning process

Report from Forum held in Kingston – November 6, 2004

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

Individuals and Families

It is critical that every individual has the opportunity to ask for and receive the kind of help or supports they wish.

People who have a disability have a responsibility to support others, to lead by example and perhaps provide peer friendships.

Families should be supported to provide traditional family (home base support) as other families do. Families should encourage independence and not dependence
To let go – to try to help the person become part of community. The difference between younger and older families needs to be recognized. Young families are demanding more from communities - Children are integrated in schools but then schools dictate what inclusion looks like – need to work with school boards.

The Community

We must also look at the community as a family “It takes a community to raise a child”. We must believe that individuals in the community will take responsibility to provide support to people with disabilities.

We will need to educate individual citizens to help them understand their role in supporting people who have a disability. There is a need to invest in public awareness to make sure that the public knows what their responsibilities are.

The Provincial Government

Different part of governments treat people with disabilities differently and they treat them differently than other people. Direction needs to come from the government as a whole to mandate responsibilities of different ministries and provide clear direction as to how people who have disabilities should be supported.

Must start by including children in all elements of community from day one. Ministry of Education must teach all children in the early ages of school about inclusion of children with disabilities.

Health and social services are creating duplication of services by not working together.

Access committees (ODA) need to recognize that intellectual disability is a disability and that not all barriers in the community are physical.

Government needs to develop tools to manage waiting lists (standardize).

The government must ensure that the transformation planning document does not get locked in but can change over time as needed.

Local Government

Municipal government – In some communities people are allowed to participate like any other child (camp programs, etc.). Other communities expect that the person comes with support. The government should consider mandating equality and responsibilities of municipalities to include all people.

Local planning committees must include individuals with disabilities and family members.

Question #2 - What Strategies and resources would help individuals receive seamless supports throughout their lives, including points of transition?

Strategies for Individuals and Families

Investment should be made in resources for empowering families. Resources should be provided to families to allow them to respond to needs as they emerge and not wait until there is a crisis.

Families are always asked to focus on concrete (what program do you want for your son or daughter?) rather than abstract. Families should be encouraged to dream and strategize about alternative ways of supporting their family member.

The changes that each person experiences in his or her life is unique. Support for transitions through life should be defined by need rather than age.

Supports should be arranged and provide in a fashion that responds in an intimate way to individuals, families and communities. Creating super service providers would not be appropriate or helpful.

Many people do not have families – we must address the advocacy needs of those that don't have families. Further, some families are spread out within many communities – must find other ways to support individuals without families.

We should seek strategies to help aging people stay in the neighbourhood where they have spent their life.

Better linkages between schools, services, families, colleges so that people know what opportunities are available to them.

Strategies for Communities

There is currently a lot of service planning through access centres, but no services. Planning should focus on using other community resources and must recognize that supports are not only provided by service providers but by friends, family, community members and through many other resources in the community that other citizens rely on.

Work must be done to increase understanding of and sensitivity to the needs of people who have an intellectual disability on the part of communities – town councils, schools etc.

Strategies for Government

Government must create greater inter-ministerial connections to address issues related to intellectual disability. For example, the MCSS transformation process cannot succeed if the Ministry of Education is not engaged in the transformation exercise. Without the cooperation of the Ministry of education to ensure the inclusion of students with disabilities in regular classrooms, we will continue to perpetuate dependency on the traditional kinds of services that MCSS currently operates. Ministry of Education is key to ensuring that future generations of students who have an intellectual disability grow up with the relationships and resources to live more independently in the community.

Employment is a key consideration. Currently not enough planning for employment beyond school. Government needs to enhance current employment services in addition to creating new ones.

Government must speak with senior parents to assess their unique needs.

Stop creating programs that isolate people from community and that people therefore then need to transition from.

Must stop the assumption that when people enter adult services the services “own” the individual. Programs provide people support to participate in the community – responsibility for supporting the person is shared with the community.

Expect other Ministries to pick up their responsibilities (housing for instance) making more funding available within MCSS.

Stop reinventing the wheel creating services that are already available for the general public.

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

Special Services at Home has some excellent qualities, it is somewhat portable and can often meet the needs of families – it is, however, sometimes difficult to access. People wondered if SSAH might be a resource to planning. Some families need assistance with the supervision of SSAH to ensure the funding is being used in most effective way. The appeal process for SSAH needs to be reviewed.

Individualized funding needs to be expanded – SSAH should be expanded including more money.

Some families do not know that SSAH exists – there is a need to educate families of available funding to ensure equity.

The portability of SSAH is a desirable characteristic that should be available to funding provided beyond the time the individuals lives with family

Foundations funding has worked well in some places but not others. In some cases it has proved to be a flexible way to fund creative and innovated ideas. In other cases, it has paid for segregated options and has created something that people need to transition from. Foundations funding should be available at a younger age and be coordinated better with the school system. Some participants expressed the opinion that Foundations, funded through MCSS, lets the Ministry of Education off the hook for preparing students with disabilities to prepare for life after school. Review of foundations programs should result in action if funding is shown to not be achieving the goals of the program.

Question # 4 How should a reasonable level of funding for an individual be determined?

Participants were adamant “We Don’t want Levels of Support” (LOS)! Any funding must be based on a concrete plan done for an individual and focused on individual needs.

Planning should be done by an individual person – someone not tied to an agency that provides supports. Costing for plan might be provided by an agency or the family.

Plan needs to be objective - not based on characteristics of the persons disability, but on need. Equity of outcome, not equity of dollars.

Most current programs are block funded. Independent planner might be used to negotiate the individuals share of block funding.

Participants suggested that the question “what is reasonable?” is a problem.

What is reasonable today, may not be reasonable tomorrow – how do you fund changing needs? The question also might lead to identifying what is the reasonable minimal standard for quality of life?

We must build in an expectation that people's situations will change over time.

Rarely to families or individuals ask for more than they need although some participants contended that traditional programs tend to. Individualized funding provides the person greater control over supports.

Income support provided through ODSP is inadequate – if it was better, people could avoid some of the challenges that we fund through other funding

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

Planning Considerations

Planning for change must consider differences between rural and urban – i.e. cost and availability of public transportation. Transportation funding is available if you are going to get a job – it should be available for other community experiences as well.

Government should develop a multi-year plan to evolve away from congregated community options in the same way as it established a long-term plan to eliminate institutions.

Government should provide multi-year funding to allow longer term planning and implementation. An accountability mechanism should be developed along with the multi-year funding commitment to ensure that funding is spend according to established principles.

Government must have faith in the sector to do the work and not to try and micromanage. There should exist a mechanisms to manage at the regional level, but with each regional office following provincial principles and criteria.

Advocacy must be ongoing to ensure that citizenship rights are respected.

Families must be brought into the community planning processes so it is not just service providers that control funding.

Planning must be a “living document” that will change over time.

Provide funding for innovation.

Funding Considerations

Current system for allocating support funding is not equitable across the province – distribution is based on historical information not current need.

Day support programs should focus on connecting people to community options. Need to continue to provide day respite for some individuals but this does not always result in quality supports. We must work to make supports more flexible so that they can respond to individual needs better and provide greater connection to community and a higher quality of life.

Government should stop streaming money to specific programs. i.e day supports, adult group home, etc. We need to unbundled money that is currently provided to agencies as block funding. By doing this we could create more individualized supports and attach the resources to each individual. Funding needs to focus on individual need. Along with this must come flexibility. We cannot pigeonhole people into particular programs.

Funding should be portable – program to program and county to county.

Funding should be less compartmentalized – more flexible as long as you can demonstrate the outcomes in the end.

Funding should be allocated to supports that meet agreed upon principles. If people providing support cannot live up to an agreed upon standard, they should not be funded.

MCSS should stop funding things that are not their responsibility and ensure that other parts of government or the community fulfill their responsibilities.

Changing Perceptions

We need to change attitudes to ensure that staff recognize that a persons home is their home.

Access community options – raising awareness - people should have memberships to all of the community places that others access. Don't recreate what already exists in the community.

We must ensure that all areas of the community are educated about the inclusion of people who have an intellectual disability in our society.

Question #6 - What do you think are the priorities the government should address?

Role of MCSS and the programs that it funds should be focused on connecting people to the community and the resources available in the community (not providing alternatives to community) – this change does not imply that the Ministry is not responsible.

Housing – work with Ministry of Housing to have it take over this role.

An increase to ODSP Income Support

Flexible funding to support innovation

Standards of excellence

Day Supports – think outside the box – creative approaches (community supports)

Portability of funding

Staff wages that reflect the marketplace and are standardized within the industry

Leadership initiatives – develop board accountability mechanism to assist boards to understand their roles in moving ahead on transformation.

Evaluation of duplication of services.

SSAH done differently – for example look at West Australia model that includes a community developer and flexible mechanisms of allocating funding.

Aging families

Must make sense of what role other ministries should play in supporting people who have an intellectual disability. Some responsibility should shift to other ministries, other responsibilities should remain with MCSS.

Government must create better linkages between ministries. Share resources and stop duplicating the work of different ministries. Those providing services must consider the challenges of managing relationships to a number of ministries – it is already difficult to manage just one ministry.

Ministry to look at how it operates. Ensure more power and control over decision making at the community level.

Avoid buzz words – use language that everyone understands

Process is about changing the Ministry as well as the community and services. Ministry needs to train its own people to understand current trends, ideas and realities.

Question #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?

This is a critical piece of work (the planning process) the institutional closure is also a huge job – Ministry needs to invest in different people to lead the two processes.

We need to develop a communication strategy for getting our information about this planning process out to all members of the community.

We should figure out how to make these improvements effect all people in our society.

The Ministry should regularly check in with us on the progress of the planning process to allow the community to make sure that we are all on track with the process.

Appropriate time must be taken to ensure that process results in a quality outcome.

We must ensure that there is no consideration of keeping part of the institutions open (i.e. centres of excellence proposal in Smiths Falls)

Must address the issue of ensuring that we can find and keep qualified staff.

Report from Forum held in London – November 13, 2004

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

If each person in the community can keep it simple supporting people well will not become a big problem.

Knowledge will relieve the sense of the unknown. Reduce fear. Attitudes will come along with knowledge. Talking to communities about the ODA will help increase understanding about how to support people.

As service providers/professionals we must remember that this is about people, not about a specific profession

We must create an understanding for families to understand that it is ok to ask for help.

Resources within the community are stretched for everyone – working together makes sense for everyone in the community.

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

Considerations for individuals and families

Need to assess the needs of each individual. Use the same approaches of supporting people with disabilities as you would use to support others in society.

Make sure that funding is in place to address needs.

People should not have to fit into a mold. All people should follow a path through community not through service systems.

ODSP funding must recognize individual supports that people need.

Information and Advocacy Support

There needs to be one contact point to provide parents the information that they need to know about how to access the supports available at different points of a persons life.

There needs to be an advocate that is not from a service agency to work with each person/family that is seeking support – someone that can advocate throughout a persons life and across sectors.

We need a strong citizen advocacy process – not directed by government.

Support networks need to be fostered to ensure that there are voices within the community to inform the government on needed changes.

Considerations for government and Service Providers

Ministries need to work together.

Resources and strategies must be driven by the individual and families not by government or agencies.

Funding must be portable through services and from community to community

We must increase the availability of specialized knowledge for supporting seniors

Training for professionals – teachers must be prepared to provide supports to students with disabilities. Support must be available for students as they progress into life after school.

There needs to be more resources available for training of staff. Training must be according to individuals/community needs, not directed by government needs.

Question #3

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

Need to be responsive to cultural diversity of each community.

Need to have summer programs to introduce 16 year olds to summer employment.

For those beyond the age of working and where employment is not a reasonable option, we need other mechanisms for supporting people that are not within the sheltered systems.

Home programs need to be given a greater priority and given as a first option.

We should build on good elements of SSAH. Some of the current problems with SSAH are: under-funding, staff turnover, families can't find support people, we can't spend all the money.

SSAH should be coordinated within the community by the agency that is best positioned to do so. Families should have a choice of what agency administers funding.

Government needs to recognize that with respect to SSAH funding, the support that people need remains over time. There must be a more sensible way of allotting hours to those that have been on the system for years. Must be different forms for children and adults. And different forms for physical and developmental handicap.

There needs to be options in the community to choose from. Individualized funding will not help if there is nothing to spend it on.

Funding needs to be portable – connected to the person and moves with them. Need to ensure that services are equitable and available across the province.

Need to protect the people that are currently within our system that may not make changes very quickly – do not want to put their support in jeopardy but do not want to give the ministry the message that we are protecting our turf.

We want community charitable organizations to remain viable places to commit public funds.

Must develop greater trust in the availability of funding so that families will accept less funding in years that it is not needed with confidence that it will increase when needed.

We should always talk in terms of supports not programs.

Question #4 - How should a reasonable level of government funding for an individual be determined?

Raise the level of ODSP.

Supports should be outside of ODSP.

There should be a basic amount of funding provided to each person to supports planning and a minimal entitlement for support that is flexible portable and transitional depending on the stage of life.

We could consider basic levels of need High, medium, low need. – we don't want a blanket level. For example – we do it in Unemployment insurance, OAS. We could call on the people who understand these types of system to assist us in developing an approach for developmental services.

Need to be careful to avoid approaches like the Levels of Support system that was suggested a few years ago.

We need funds that help people be better included in community including investment in the community.

Money must be based on the individual plans and be directed to help connect people to community.

Must address the disincentives in the current system. Do this in a way that does not trap ourselves and work at cross purposes to our other efforts

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

Increased opportunity for social participation and healthy life styles. Including meaningful work recognizing the limitations of many people. (some to do part-time)

Everybody needs to feel useful and valued.

Need more support for parents and families. Ministry needs to recognize the added stress on families to ensure a semblance of a normal life.

Need more specialized housing (children with Autism).

Would like to see more innovative housing. Continuity in in-home services – people should not automatically move into adult services. In some cases, SSAH should go into the community.

ODSP income support needs to be increased to help people live more independently.

SSAH workers should have access to mileage support for travel. (not provided in some communities)

There needs to be more funding of accessibility and for providing aids.

We need flexibility with respect to respite services. (should be more responsive to families) should respond to crisis situation.

There should be help available to equip houses for people to live within the family home.

Better wages for staff in the sector to help attract and maintain staff.

People should not have to leave home to access the support they need.

Need more individualized support – less congregated, segregated supports.

Decision making should be made at the local level, but those at the local level must have good information on which to base their decisions. Planning starts with a person and decision making should be local – learn from some others on this Australia, BC.

Question #6 - What do you think are the priorities the government should address?

Issue of freedom from harm and abuse – if people are embedded, they will be safer.

Need Premier to drive a cross ministry initiative to change support for people in all areas of life. Mechanism for integrating the action between ministries.

Closure of institutions – should be reiterated as a top priority.

Increase funding to programs and make it flexible and individualized so that families and individuals can be creative.

Recognize that those in traditional support may continue to need these supports.

Need funding for infrastructure – for example support for families with employment relationship under SSAH.

Incentives for employers to hire people with disabilities.

Affirmative action approaches related to employment.

Need Premier to understand and endorse approaches so that the ideas will trickle down to other parts of government.

Support for people in their housing accommodations, not just bricks and mortar. Should be about individual choice. Many choices available. Provide supports for individuals to live where they want.

Ensure that support is available within the family home with the family?

Day Supports – SSAH working well for most families that receive it. Needs to be portable and available once they have left the family home.

Increase funding to address waiting lists.

Aging Parents – Families are going day to day not knowing what the future will look like, need peace of mind.

Funding for medical supports is different for many people with an intellectual disability such as dental care, drugs. Must look at these individuals and their health need separately from other citizens.

Funding and support for innovation. Government used to invest in pilot projects and best practices. We need an opportunity to try out new things.

Question #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?

We need to invest in leadership to ensure the future wellbeing of the sector.

Many people have a dual diagnosis. There is inadequate funding for diagnosis and staff training.

There are many young people in long-term-care facilities. This must stop.

There are children in care of the CAS simply because other funding is not available .

Need to assure a realistic level of funding for those coming out of institutions.

Need to rethink the definition of an institution and look at how we are institutionalizing people within the community.

Need to ensure that we respond to those that are not always able to articulate their needs (emergency systems).

We must address the long waiting list for psychiatrists and provide psychiatrists with appropriate training on issues related to people who have an intellectual disability.

Report from Forum held in Richmond Hill, November 13, 2004

Key Points Addressed at the Richmond Hill Session

Participants characterized their attitude about the transformation process as being one of healthy skepticism. The process will only be successful if there is a commitment by government to provide the resources to carry out the plan. While there is agreement that future directions must focus on creating greater community capacity for the inclusion of people who have an intellectual disability, this must not be viewed by government as a “cheap” solution; appropriate investments must be assured.

Real transformation implies a paradigm shift – a new way of thinking and acting. We will need to work to ensure that everyone hears and understands the new paradigm.

Responsibility and accountability needs to shift away from the system to people with disabilities.

Need to work with all stakeholders and involve other key ministries in the transformation process.

Shared goal with government commitment must be the elimination of waiting lists and provision of mandatory funding for people who have an intellectual disability as full citizens.

Long range plan must be open ended – living document.

Additional Key issues discussed:

- Funding availability flexibility portable and individualized - more
- Review of legislation regulations and policy in order to increase access and flexibility- age barrier and ODSP claw back
- Resources for community capacity
- Global funding and affordability
- Revising the entire ODSP system and include an annual Cost of Living increase
- System flexible individual and responsive supports and affordable in the community and includes funding
- Inter-ministerial cooperation - collaborative planning which leads to inclusion in education, health care and housing and social supports
- Seamless transitions
- Funding changes as needs change as long as needed
- Waiting Lists

- Develop an accountability tool for equitable sustainable and portable funding for individual needs and TPA services
- Accountability tool – tri-level identification process with range of services and \$\$ available at each level
- Re-evaluation process that is a timely regular automatic and available due to crisis or at the transition stages
- TPA – accreditation process - encourage the use of the TPA services rather than purchasing services
- Support and enhance existing services
- Change legislation
- Legislative changes that support the creation of the resources and fund supports
- Mandating basic level of services including but not limited to residential, SSAH, ODSP, through multi year funding
- Ombudsman with access to money and services to support individuals through crisis
- Legislation and policy amendments which require service mandated and inter ministerial cooperation
- Supports and funding flexible accountable and affordable and ensure entitlement
- ODSP – a reasonable level of funding that supports true citizenship
- Resources for capacity building
- Ensure extensive planning takes place for each individual and adequate resources available over a lifetime
- Collaboration of key ministries

Questions

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

Government role to ensure:

- flexible of funding
- Access to supports
- Collaboration between ministries
- Funding that is tied to an individual throughout life – related to citizenship
- Equal access to services regardless of where a person lives
- Entitlement for families to ongoing planning
- Family involvement in planning process
- Guaranteed right to choose where and from whom a person receives services
- Individual and flexible supports to people and their family member with a disability
- That government listens

Families and individuals have a responsibility to work towards broader community awareness of the place that people who have an intellectual disability play in our society and the support they need to participate.

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

- Third party planning vs. facilitation
- Global budgeting
- Remove age barriers to services in DS sector
- Transition barriers removed
- Graduated transition to employment
- Safety net for employment to become embedded in society
- SSAH to ODSP seamless
- Updated antiquated legislation
- Fund and provide resources so individual can be self sufficient
- Choose where they live
- More funding for senior services
- Development of community to include and develop citizenship capacity
- Province must mandate philosophy embedding individuals in community

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

- Elimination of wait lists
- Priority more funding
- Parent participation in decision making for their son/daughter
- Flexibility – more program options
- Funding formula – per capita/geographical
- Inclusion
- Greater involvement of community
- Clarity for the community
- SSAH – needs to be looked at what is working well/consistent funding levels – address wait list
- Choice of support at home vs out of home care
- SSAH funding needs to be responsive to need

Question #4 - How should a reasonable level of government funding for an individual be determined?

- Level of support inconsistent
- Needs analysis
- Move away from squeaky wheel

- Unified approach to determine need
- Funding flexible to address life changes
- Precedent to funding individual need through SSAH
- Defined framework – identify money and services available at various levels
- Funding mindset needs to change from crisis response to quality of life
- Identify goals that define quality of life
- Accountability measures for individual and program
- Flexible funding to individual approaches and need
- Develop a process on a societal level for government to respond to life evolutions
- Developmental Services Ombudsman
- Mapping tool to identify levels of necessary funding based on established criteria

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

- Mandated and seen as an entitlement rather than families being most in need
- Persons needs rather than system need
- Consistency across regional offices
- Community responsiveness
- ODSP – revenue claw back – enabling to live above poverty level
- Families able to direct services rather than having to convince other they are most in need

Question #6 - What do you think are the priorities the government should address?

- Resources for community capacity building linked to other ministries – education/health/housing
- Inclusion - Funding innovation and systematic change – agencies to be funded to be the linkage for community to enable inclusion
- Housing affordable creative
- Enhancing SSAH

Question #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?

- Funding for agency pressure points exiting and not available

- Ministry needs to get away from penalizing agencies who are able to save money in year – not have to spend until next when it could be used more effectively
- Strike while the irons is hot
- More time for thoughtful planning in future