

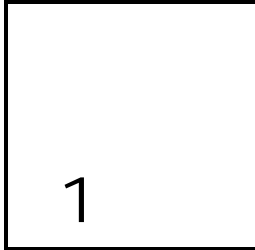
November 2006

Summary Report  
Consultation on Transforming  
Supports in Ontario For People who  
have a Developmental Disability  
Ministry of Community and Social Services

**MERCER DELTA**  
Organizational Consulting

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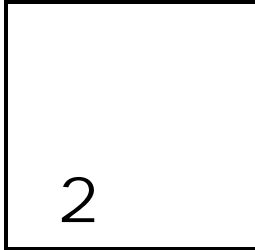
## Introduction

The Ministry of Community and Social Services (MCSS) is undertaking a fundamental shift in the delivery of services to adults with a developmental disability. This transformation has been based on extensive consultation which has helped to define strategic changes needed to achieve the objectives of fairness, accessibility, and sustainability in the transformation of the sector.

As reforms have begun taking shape, the Ministry prepared a Consultation Paper - "*Opportunities and Action*" - which was used to both inform stakeholders about the progress of transformation as well as to stimulate dialogue and feedback regarding the proposals. To support consultation on "*Opportunities and Action*", the Ministry retained Mercer Delta Organization Consulting to help facilitate an external stakeholder consultation process with family members and individuals with a developmental disability that will support the successful implementation. The consultations aimed to solicit the views of a wide range of stakeholders within the developmental services system, establish and sustain momentum within and outside the Ministry for the reform process, and promote the active participation of stakeholders in the development and implementation of the new system.

The scope of Mercer Delta services included the following activities:

- Develop and implement a broad public consultation across the province within a short timeframe, including approximately twenty roundtable sessions with individuals and families of individuals with a developmental disability
- Support the Ministry with the coordination, evaluation, and analysis of the feedback that the Ministry receives through the roundtable as well as via web-enabled or document-based consultation
- Consolidate findings into a report on consultations, including key findings, analysis and recommendations.



## Background –Transformation of Developmental Services

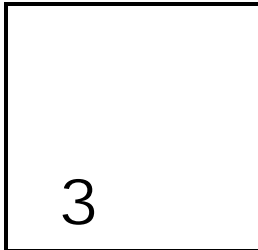
Ontario has a long history of providing support to people with a developmental disability. Over the past century, services have evolved and present-day supports focus on assisting individuals who have a developmental disability to live as part of their communities.

In September 2004, the government made a commitment to transform the province's system of developmental services and began a process that would incorporate input from people with a developmental disability, their families, agencies and individuals that provide support, advocates, and members of the community at large. Together, these groups would provide valuable advice as the government created a plan for a fair, accessible and sustainable system of community-based supports.

On May 2, 2006, the Ministry of Community and Social Services released a consultation paper - *Opportunities and Action* - which was used to both inform stakeholders about the progress of transformation of supports for people who have a developmental disability, as well as to stimulate dialogue and feedback. The paper also provided information about the ministry's plan for systems transformation in the areas of:

- Accessing supports
- Eligibility for services and supports
- Application for funding supports
- Funding approaches.

*Opportunities and Action* continues to be available for viewing on the publications section of the ministry's website at [www.mcscs.gov.on.ca](http://www.mcscs.gov.on.ca). The following summary is a collection of some of the themes and general comments we heard during the consultation.



## Overview of the Consultation Process

We consulted in two ways – in person and online (web-based) feedback on the consultation paper.

A total of 24 face-to-face sessions were held across the province including three French-language sessions (see Appendix 1 for a list of locations and meeting dates). These meetings were intended for individuals with a developmental disability and their family members.

In total, the sessions were attended by more than 500 people, with session sizes ranging from 6 to 44 participants. Many families attended the sessions in response to invitations from the ministry's regional offices (over half in most cases), but there was also significant attendance by people who heard about the sessions via a provincial organization, their service agency or word of mouth.

There were three francophone sessions held in Sudbury, Ottawa, and Kapuskasing, and there was often broad cultural/ethnic diversity evident in the English sessions. Most sessions had a mix of younger families taking care of children and young adults (i.e., under 21), but there were a few sessions with a majority of older families that were caregivers for adults with a developmental disability. Some sessions included individuals with a developmental disability, their siblings and grandparents, and there were also a large number of families with more than one child with a disability.

Extensive written input was also received.

We also received a large number of submissions from individual service provider agencies and/or their staff (close to 100), as well as a limited number (10-15) of submissions made on behalf of advocacy groups or associations.

Over 550 hard copy and electronic submissions were received, but since some of the single responses from agencies represented the views of hundreds of families that were consulted, the coverage is considerably broader and more representative of stakeholder perspectives. Together, the face-to-face consultations and written/web-based submissions totalled over 1,000 responses from individuals, families, agencies, and other organizations.

The themes presented in this report represent a diverse range of views that were expressed rather than a “majority view.” This provides a valuable insight into the unique perspective of each family, the diversity of sector stakeholders, the intense passion and commitment of everyone who participated and the impracticality of trying to design a “one-size-fits-all” solution to the serious challenges faced by individuals with a developmental disability. The consultations have generated a rich diversity of suggestions, ideas, concerns and other views that the ministry can use to inform and accelerate its transformation of the developmental services system in Ontario.

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## What We Heard - Highlights

- Participants appreciated a “chance to be heard”, partly because of interest in the developmental services (DS) transformation, but also because the consultations allowed families, individuals and agencies a chance to express their goals, ideas, frustrations, and in many cases, deep emotions within a supportive forum.
- There was broad support for the proposed transformation of the developmental services system, including support for the principles such as fairness, accessibility and portability, sustainability and system changes including streamlined access, and direct funding.
- The consultations revealed a case for change. Participants reported urgent family needs not being addressed, significant under-funding and evidence of unfairness and inequities.
- There were many suggestions in all of the seven consultation topic areas. See the following section for specific comments on each area as well as a summary of comments on the access system, the general lack of adequate supports, the need to increase compensation for caregivers, the seriousness of personal hardships and a desire for more individual control over funding and services.
- There were different views about “how to” implement reforms, particularly direct funding, independent planning, single point access, quality control and accountability.
- There was also an unintended but positive outcome of the family sessions which was the opportunity for family networking. The sessions provided a forum for participants to talk about and share feelings regarding extremely difficult personal circumstances with an understanding audience. There were examples in virtually every session of families exchanging email addresses and making plans to get together following the session to discuss services, help each other and discuss shared coping strategies.

## Changes to the current developmental services system must be made

The consultations strongly supported a case for change. Participants reported urgent family needs not being addressed, significant under-funding and evidence of unfairness and inequities. As well, **there was broad-based support for strategic changes proposed as part of the transformation.** Most families, individuals, agencies, and associations expressed strong support for the transformation and endorsed a number of the key elements such as fairness, flexibility, choice, sustainability, streamlined access, and direct funding. There were some families, individuals, agencies, and associations that expressed concerns, but these were a clear minority of the views presented.

## Urgent needs are not being addressed

The challenges being experienced by some families trying to take care of their children at home are unsustainable. To the extent that support is inadequate, then families will have “no choice” but to give up their efforts to take care of their adult sons and daughters at home. This is a negative outcome from the perspective of families who would prefer a situation where living at home is ideally a positive experience.

From a sustainability perspective, there is an even more urgent case to be made because at some point the parents, without adequate support, will no longer be capable of taking care of their adult children with a developmental disability. The frustration level will become too high and the financial burden too onerous to shoulder in which case the province will be faced with an increasing demand for more expensive agency-based residential accommodation options.

## The developmental services system needs additional resources

Families, individuals, agencies, advocacy groups, associations, and other organizations were unanimous in their call for greater resources within the developmental services sector. The funds might be for families and individuals to purchase needed services, or for agencies to train and retain staff.

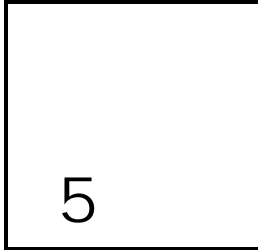
## Unfairness and inequity exist in the current system

Another clear rationale for continued commitment to change is the current unfairness and inequities that exist in the system. There were examples of families and individuals with identical needs receiving significantly different service levels – an unfair and unsustainable proposition. These inequities can arise from different family income levels, from regional variations in services, from at-home versus agency setting differences, and even from differences in service quality standards among agencies.



## Cautions about implementation

Despite the overall support for general themes of the transformation (citizenship, fairness, sustainable funding, streamlined access, direct funding), there were also important differences of views regarding the specifics of how to implement any changes. There were different views expressed regarding direct funding, independent planning, single point access, and direct purchase that urge caution with the implementation of these components of the transformation.



## Summary of Discussion Themes

The consultation results provided many views and opinions from across the province. The diversity was reflected both in terms of provincial coverage, with different communities expressing their unique perspectives, as well as different individual and family demographics. While there were a number of common themes that emerged from the sessions, there was an equal diversity of views that resist generalization – a reflection of the diverse local circumstances and individual situations of family members.

Based on the consultation objectives, feedback was requested in seven topic areas:

1. Support for inclusion and community engagement
2. Respite services for caregivers
3. Partnerships with families on residential supports
4. Transition across life stages
5. Supports for people with specialized needs
6. Taxes, wills and disability savings plans
7. Quality supports and services.

In addition to these seven topics, the respondents were also invited to express their views on other topics that were considered important. These views included comments on the access system, the general lack of adequate supports, personal hardships, and a desire for more individual control over funding and supports, and general views regarding the transformation.

## Support for inclusion and community engagement

Through previous consultations, the ministry heard that individuals, families, agencies, and government need to work together to strengthen the voice of people who have a developmental disability and make it easier for them to participate fully as citizens in their communities.

Overall, the participants felt that there have been improvements to community participation and integration. However, there still remain a number of physical, economic and cultural barriers to full participation. The most common theme was that community participation requires meaningful activities, employment and friendships.

Transportation was cited in virtually every session as a significant barrier to community participation. In rural areas, there were numerous examples of long drives to participate in community programs that have two negative impacts. First, was the cost and time involved in transportation because many programs did not include transportation, so this fell on the shoulders of parents. Second, program participants were not able to build relationships with people in their own community because they had to go to a larger centre to participate in the program.

In urban areas, transportation was also an issue since public transportation services may have been cut or scaled back resulting in additional hardship for families who need to drive their children to different programs while at the same time trying to retain a job.

The consultations indicated that there are still a number of physical and attitudinal barriers to full participation. As a result, agencies have been modifying programs to improve community participation to the extent that they can within existing funding levels. The most common theme was that community participation requires adequate funding and appropriate supports to be successful.

## Respite for caregivers

Respite is supports available and needed to give families brief breaks from caring for an individual who has a developmental disability.

The ministry heard that the system is very complicated and could be made both simpler and more effective. Consultations revealed a need for more funding, better quality and stability of staff, and flexibility and choice rather than a “one size fits all” form of respite services. An ideal system of respite supports should offer a choice of respite services in addition to flexibility and responsiveness to the realities of caregiver needs.

**Participants expressed a need for choice** and a range of respite relief services from caregiving responsibilities, including weekends off, annual vacations, short term evening breaks and a wide range of short term “emergency” respite services. Respite is about

providing the family with a break, but it also provides the individual with a break from his/her caregivers.

**In-home and out-of-home respite services are both needed** depending on individual circumstances at home, and the type and intensity of required support needs.

**Access to qualified and trustworthy respite caregivers and the ability to pay higher wages** were frequent barriers, and families expressed a need for better employee screening, which might address current problems of retraining new workers. Respite workers should be professional and well trained in order to be trusted by families and understand the needs of the individual.

**Examples of respite working well** and/or suggestions for respite:

- Easter Seals camp
- Small group respite
- Drop-in centre
- Allowing younger family members to provide respite care and making kin-care respite services eligible for high school student “community hours credits”
- A “hotline” for emergency situations and to act as a resource of respite providers available in the area
- A website where families can post a want-ad for respite service.

**More funding is needed for respite.** Many families noted that the hourly rate associated with respite under the Special Services at Home (SSAH) program is so low that it is difficult to secure workers on an ongoing basis (worker may gain experience, but then moves on). To overcome this problem, families often “top up” the hourly rate with their own money; in many cases, they pay for respite entirely themselves, and costs can be high, which impacts upon the amount of respite they are able to purchase. Another common situation reported was that the SSAH funds lasted only part of a year and by mid-contract, families had used up the SSAH and either had no further respite or were required to pay for the service entirely themselves.

**Emergency respite services were viewed as generally lacking** because it was only in the direst circumstances that families could qualify for emergency respite services. In addition, siblings move out of the home and sometimes community (e.g., in northern Ontario), so the family support system has shrunk. All of these situations could be considered “emergency” in that they are unpredictable and, if not addressed, could lead to significant problems.

**Red tape and inconsistencies.** Concerns were noted about restrictions and differences between certain respite programs (e.g., SSAH, Enhanced Respite, Community Care Access Centre respite) and the difference in respite programs for children and adults with a developmental disability.

**Better day programs reduce the need for respite.** Many respondents noted a relationship between the quality and adequacy of support services and the need for respite services. Ideally, if there were adequate and appropriate support programs, the need for respite services would be dramatically reduced.

## Partnerships with families on residential supports

The topic of residential services was of interest in all the in-person meetings. Discussions explored how the province, families and other organizations can best collaborate to support individuals' living arrangements when they are ready to move outside the family home.

Discussions regarding the availability and adequacy of residential arrangements were diverse. Most respondents indicated a general shortage of appropriate residential services. There were some examples of innovative partnerships that have been achieved and it was recommended that they be recreated across the province.

**Currently residential choices are extremely limited** and fall into the general categories of group home, family home, supported independent living and staying at home. Virtually all community sessions revealed a clear frustration with the availability of fully funded agency supported group arrangements, and in particular, the extensive waiting list to find a spot. More choices are needed. Most agencies, advocacy groups and organizations confirmed a general lack of appropriate residential services, and argued for a more diverse range of accommodation options to better address needs. Respondents confirmed the need for a combination of appropriate living arrangements combined with appropriate supports.

**Suggestions and partnerships** cited during the consultations included:

- A family invests in a home for their son/daughter and then this home is used as a “home base” for support services for the person living there. The home could also be a focal point for day services offered to other people with similar needs that come to visit each day or potentially share accommodation with the person whose family owns the home.
- Families working together to investigate innovative residential options (i.e., a research and ideas sharing network).
- Greater flexibility in residential options that are available and openness toward creative options.
- Apartment complex for individuals with a developmental disability, or for individuals with a developmental disability to live with others. The complex could be rent-geared-to-income.

- Co-operative in Pickering with 7-8 individuals with a developmental disability and about 80 others who agree to support them as part of living in the co-op.
- Lease-to-own agreement with a real estate agent in St. Marys.
- Multi-generational house.
- Granny-flats.
- Habitat for Humanity-type scenario where individual/family could secure a low-rate mortgage.
- In Brant, 11-12 unit apartment with common areas (living, dining), including one apartment reserved for “house parents” and one unit for staff.
- To offset costs, consider a requirement that new housing developments include a group home which could be donated by the builder.
- Pooled resources among families to provide support.
- Use empty schools for residential or day supports.

**Numerous barriers to innovation.** Despite some examples of innovative successes, the general tone of discussions revealed significant barriers that discouraged the creation of innovative residential options. In particular:

- The lack of appropriate support services that would be needed to parallel an innovative residential option.
- Zoning by-laws and other land use regulations that preclude the creation of accessory apartment units or “granny flats” that could be appropriate and low cost innovative residential options that provide privacy, independence, as well as proximity to support and safety.
- Need for more individual choice about where and how to live. Some people do not want group homes but it is all they are offered, and there is a sense that residential solutions tend to reflect “what is available” rather than “what is needed.”

**Not enough spaces and long waiting lists.** Concern was expressed for the lack of availability of residential spaces; long waiting lists, and perception that lists are getting longer. Families would like to be able to plan for the future before their living situation reaches a crisis point, including residential support, but they are unable to do so because of waiting lists.

**Safety and security of vulnerable people** were expressed as critical concerns with respect to all residential options. Parents are keenly aware of the vulnerable nature of their children (both adult and younger individuals).

**The value of family networks** was reinforced during discussions on residential accommodation options. Specifically, where families group together to share ideas, and in some cases financial assets, the ability to generate viable residential options is enhanced.

**A collaborative effort.** Organizations indicated that families and the ministry have a major role to play in supporting innovative residential options, but they also recognized that as primary service delivery partners, agencies have an important role in providing necessary supports to make innovative living arrangements more viable.

## Transition Across Life Stages

One of the most urgent issues for discussion concerned the difficulties associated with “life transitions” when a young person leaves school or when an adult becomes a senior citizen. Making the adjustment to different support needs and different sources of support is clearly difficult and the consultations strongly suggested a need for improvements to find better ways to help individuals and families plan for these transitions in advance, and make them successful.

**Concern and disbelief regarding the lack of transition planning or supports to help manage across life stages.** The disbelief stemmed from the fact that most of the anticipated difficulties are predictable impacts of demographic aging factors. A clear concern was expressed about the system that tends to respond to life change events as they occur, rather than more proactively planning for the transitions before they occur.

**Families need to start planning earlier.** Much better information is needed to support transition planning, especially for the transition to adulthood. Families and organizations shared the view that the system tends to respond to life change events as they occur rather than more proactively planning for the transitions before they occur. Individuals with a developmental disability and their families need to participate in program planning to the fullest extent possible, including getting connected to support agencies as soon as their children are identified as having a disability. Families should learn advocacy skills and begin to think about long-term planning when their child is young.

One of the most significant gaps identified was the **lack of support for transition into adulthood.** This view was expressed in numerous ways but focused on the fact that individuals with a developmental disability are generally receiving an improved, and in many cases, good quality of day time support through school up to the point when they reach age 21. After 21, numerous families referred to “the cliff”, where there is a significant and dramatic decrease in the level of supports available, but not necessarily a decrease in the individual’s need for supports. As a result, much of the progress made in

developing an individual's independence and quality of life can rapidly regress because there is "nothing to do" except sit in front of the TV. This is both highly stressful for the caregiver, as well as regressive for the individual with a developmental disability. Some successful examples, such as progressive school boards and partnerships among service providers were mentioned by families, but these were an exception, rather than the norm.

**More inter-ministerial collaboration is needed.** A related comment made by numerous family members is that the Ministry of Community and Social Services needs to work more closely with the Ministry of Education in planning transitions from school to adult supports. In every session, families expressed dismay about the lack of co-ordination and integration between the school system transition planning and community supports.

**Agencies need to collaborate with families and one another** to ensure that the needs of everyone in the family (siblings, parents, etc.) are being addressed and that there are adequate services without duplication. Schools and agencies need to work in partnership with families to ensure consistency and the necessary range of supports and help with planning.

**Ideas and suggestions** to improve transition across life stages:

- Planners or case managers who are aware of services available in the developmental services system need to get involved in the school-sponsored planning process while the individual is still in high school.
- Consider focusing not on special programs, but on what a typical student does after school – promote inclusion in this way.
- Create an infrastructure for providing better information to families, individuals and caregivers about the likely impacts of life events and how to plan for these events.
- Continue cooperative education placements after school ends to help with transition to community.
- Support the creation of family networks.
- Provide support services on a "continuum", rather than a program-specific basis to build a support service system that is person-focused and holistic rather than program- and ministry-focused.

**Aging caregivers and aging people with a developmental disability.** The other significant life event discussed during the sessions was the impact of aging caregivers.

- Caregivers expressed concern about their physical ability to continue providing support for individuals with a developmental disability and fear about what happens when they are no longer able to provide support.



- Numerous family members cited a concern that their child was very dependent on a stable home environment and that it would be a “rude awakening” for them once their parents were no longer the primary caregivers. Suggestions were made about the importance of supporting aging parents by gradually building up independence, trust, and support services with an out-of-home network of caregivers and friends.
- Support needs for seniors are different than for younger adults partly because aging at-home caregivers may want to retire, but also because support needs change with age. Families would like to see developmental services supports more available in long-term care, when long-term care is appropriate for their family member (i.e., because individual is a senior).

## Support for People with Specialized Needs

Specialized supports, beyond those available through community, mental health and counselling services are needed when people who have a developmental disability also face mental health, physical disability and/or behaviour issues.

**Need for more inter-ministry coordination.** This topic generated considerable discussion about the need for ministries to collaborate more effectively. Whether it is between the Ministry of Community and Social Services and the Ministry of Education or the Ministry of Health and Long-Term Care, there was a clear call for the need for a much more holistic and person-centred approach to service delivery. There were numerous personal stories of individuals “falling through the cracks” between ministries that could have been avoided if a more client-focused approach was used to integrate the various supports and services into a well planned system.

**Different definitions of “specialized” supports and services.** Many attendees had their own definition of “specialized resources” or “specialized needs”. Most people understood a common definition that the ministry typically uses which focuses on dual diagnosis (individuals who have a diagnosed developmental disability and mental health issue), individuals requiring complex and atypical supports and services. However, many families had different definitions and spoke of the “special” supports that their son/daughter required.

**Difficult access and availability of specialized resources in northern and remote areas.** This topic was one of the relatively few that revealed a significant regional variation in opinions. For northern and remote communities (sessions held in Dryden, North Bay, and to some extent, Thunder Bay), families were worried about the lack of support available in their community (e.g., closest Snozelen room for a family at the Dryden session was in Thunder Bay). Support was expressed for video-conferencing in Dryden and Sioux Lookout.

**Qualified caregivers and medical professionals** are needed that understand both developmental disabilities and medical or behavioural problems.

- Numerous families indicated that there are very few qualified medical professionals and caregivers that can adequately address the needs of individuals with specialized needs, especially in rural/remote areas.
- An associated recommendation by numerous families was to better train caregivers, as well as other professionals, about the unique needs of individuals with dual diagnosis.
- Several families identified that family physicians and other health professionals should receive more/better training on developmental disabilities in general and what services are available in the community, and the impact of drugs on individuals with a developmental disability.

**Extreme vulnerability requires trust and professionalism.** Another common theme during discussions was that individuals with complex specialized needs were highly vulnerable and in many cases non-verbal. As a result, there needs to be a high degree of quality assurance in terms of the services provided. This usually requires extensive training, time spent getting to know the person, highly experienced staff and rigorous service quality monitoring.

**Agencies need more funding to hire qualified caregivers** that understand developmental disabilities, in addition to medical or behavioural problems. Many agencies acknowledged the difficulty in recruiting and retaining qualified individuals to work in this area. Some service providers have an interest in promoting recruitment and retention and suggested that the Ministry of Community and Social Services should work more closely with the Ministry of Training, Colleges and Universities to explore new diploma and degree options leading to the training of additional professionals.

## Taxes, Wills, Disability Savings Plans

Many parents who have a family member with a developmental disability continue to provide financial support through the adult child's years. This discussion topic identified opportunities to better align the provincial and federal tax systems to more effectively help address the additional financial costs faced by caregivers. This included exploring the possibility of creating a registered savings plan for people with a disability. Families also spoke about changes in how they could use wills and trust funds to support a family member.

Participants indicated that families who are supporting individuals with a developmental disability face increased, and in many cases, onerous financial costs. A consistent theme was the inadequacy of current funding support when compared to the magnitude of expenditures faced by families who are caring for individuals with disabilities.

There were many suggestions from families and organizations about how to modify the current financial support programs and improve personal financial and tax systems to improve incentive structures:

- Increase the current level of funding available under the Ontario Disability Support Program and Special Services at Home, particularly for families that have lower incomes or are single parents.
- Temper down the current system of financial “claw-backs” of program funding that kick in when people receive any form of employment income.
- Make changes to the tax system that would help families cope financially;
- Monies in a trust should not necessarily have to have a third party trustee and, should be non-taxable.
- There were some discussions about innovations that could help with long-term financial planning and generally there was wide support for a proposed disability savings plan. Increases to allowable deductions were suggested for things such as transportation, accommodation, education and support workers that would make the financial burden less onerous.
- Improve information and understanding about wills, trusts and other financial planning issues associated with individuals with a developmental disability.

## Quality Supports and Services

Families, agencies, advocacy groups and associations all expressed concerns about the adequacy and availability of qualified support workers. Respondents confirmed that the current low wage structure and lack of training opportunities make it very difficult to find appropriate support workers. Family advocates indicated that it is very difficult for families to pay market wage rates with the amount of money provided under Special Services at Home contracts.

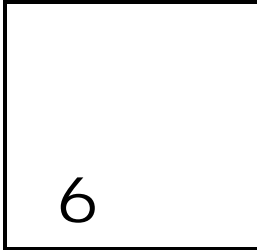
There were recommendations for higher wages, an integrated human resources strategy for the sector, appropriate training programs and improvements to working conditions. Agencies confirmed that it is often difficult to provide quality services when faced with rapid staff turnover.

**A desire to get more involved.** Families and individuals expressed an interest in becoming more involved in defining service standards and monitoring service quality of supports and services that are provided to people with a developmental disability.

Suggestions in this area called for a greater role for the province in terms of monitoring standards of care, creating a quality assurance mechanism for families to investigate service issues and developing a proactive strategy to increase and improve the calibre of at-home and agency staff caregivers.

Some families who choose to hire caregivers themselves worry about getting quality supports and would like to see a database of qualified and pre-screened workers.

Family and self-advocacy groups, as well as families themselves, argued that a quality assurance mechanism is currently lacking and that there is a clear need and desire for families to be more involved in quality assurance.



## Additional Themes Arising from Consultations

In addition to the seven main topics/questions that were posed in the consultation paper, respondents expressed their views about other aspects of the service system.

### Access

One of the most consistent themes that arose during the unstructured part of the session dialogue with individuals and families was related to the current system of access to support services. Many families felt that the current access system was not working very well. Some of the main issues raised are listed below:

- **Need more funding and service capacity to address needs.** There are diverse programs, many of which do not have adequate funding available. This can create false and frustrating expectations about the potential receipt of services that in reality are not available.
- **Simplify and streamline the access process.** Many people felt that it is extremely difficult to navigate the multiple application forms and service access points.
  - Because there is rarely a single point of access to services, parents need to spend an enormous amount of time searching for different programs and applying to numerous agencies. This creates a challenge in terms of “filling in all the forms” that essentially repeat much of the same information, but to a wide variety of agencies and support organizations.
  - Parents find the access process to be time consuming and stressful because they are also trying to provide care for their child, and in many cases, trying to hold a job. For single parents, this can be an upsetting and risky activity because they are faced with an impossible decision about whether to support their children by staying at home with them, by “running around filling in forms”, or by maintaining the stability of their current employment.

- **Many people don't know what supports are available** in their communities.
- **More informed planning is needed.** It was suggested at virtually every session that families need more informed and comprehensive support to help plan, and manage transitions and access services.
  - Many families said they were confused and frustrated. For them, any form of credible information and planning support would be greatly appreciated, irrespective of whether this help came from the ministry, a service provider or a family network.
  - Some parents wanted access to independent planners who are not associated with a particular agency (service provider) with a mandate to help families navigate the system and develop a service plan. The difficulty cited was that any single agency knows quite well what support services are provided by that agency, but few had a “system-wide” perspective on the range of formal and informal supports and services available in the community.

## Families can face extreme hardships

It was clear from the sessions that many families in Ontario are facing extreme hardships and feel like they are “falling through the cracks” in terms of service provision.

The extent of the hardship was evident by the highly emotionally-charged discussions around the topic of access to service and inadequacy/unavailability of support programs. In numerous cases, family members became extremely agitated, upset, and angry when talking about the difficulty of their personal circumstances.

- **Need more financial supports and supportive services.** Over and over again, respondents indicated that the current level of support for families living at home is unacceptable. In some cases, family members are caught in a difficult situation when their child moves from school age to adulthood with virtually no supports available. This places the family member in an extremely difficult situation of potentially having to quit their job in order to provide care for their adult child. Having to do this was both stressful and eroded the dignity of the parent and the individuals involved. Virtually every session included individuals and families that simply said that there is not enough money in the system to adequately service the need.
- **Applying for services that are not available.** One feature of the current system that frustrated families is that service planning typically includes a review of the menu of services and supports which exist within a community, but when it comes time to apply, it turns out that they are in fact not available, either because of insufficient funding or because of a fixed number of available spaces. This process of increasing a family's hopes that there may be some form of service that can provide support only

to be told that there is no room or there are no funds was extremely upsetting for many families.

- **Greater fairness and equity.** There were numerous comments about inconsistencies and inequities in the system that further fuelled the frustration and personal hardship suffered by families and individuals who are trying to access service. There were many descriptions of a “have-have not” system whereby a lucky few would have their children placed in an agency setting with a “hundred thousand dollar service” whereas other families with children having identical needs would virtually be stuck with no services. Families were particularly upset about the fact that individuals with similar levels of need and abilities would receive different levels of service depending on where one lives in Ontario, or more frequently, whether or not the family was lucky enough to receive agency-provided services.

## Transformation is welcome, but changes are needed immediately

Most respondents expressed widespread support for the ministry’s proposed transformation of the developmental services sector. In particular, the proposals for independent planning, direct funding options, portability and a single point of access were strongly supported by most respondents. Some of the benefits cited have been documented elsewhere, but include the ability for families to exercise more control over how funds are spent, including making staying at home a more viable option than moving to an agency setting. In addition, the proposed independent planning and improved access were viewed positively for their beneficial improvements to the current system of access.

It was also clear that there is an extreme sense of urgency associated with changes. Due to the current hardships faced by some families and the level of frustration and system inequities, there was a strong case made for immediate changes to the system. The most often cited comments after the ministry’s presentation at the community meetings were “how fast can this be done?” and “will there be more money?”

According to some agencies that consulted with families that use their services, there is a more tempered support among families for some elements of the transformation. These comments may reveal a difference in views between families/individuals that are currently connected with an agency (e.g., people in group homes, etc.) versus families that care for their son/daughter at home. As noted previously, the majority of families in the face-to-face sessions were caring for people with a developmental disability within their own homes, and as a result of financial hardship, confusion, insufficient supports and perceptions of unfairness, were the same families that were most anxious to change the current service delivery system. For most families, providing home-based care for their children, the “status quo” was clearly not a viable or sustainable scenario.

## Desire for more control, tempered by appreciation for agencies

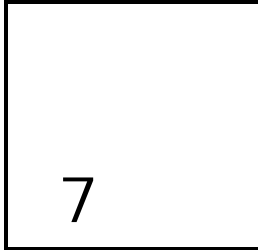
Some families want to exercise more control over how funds are spent, while others are satisfied using service agencies because of the accountability and safety issues that may be associated. Other people don't want a direct funding option to become the norm too quickly in case the availability of services is not developed – having money doesn't help if there are no appropriate supports to purchase. Some families expressed a fear that they would be in trouble if they are dissatisfied with services they obtained on their own, while at the same time, services available via agencies become less readily available.

Some session attendees spoke of their successes with, and strongly advocated for, direct and portable funding. Other families believed that direct funding would add to the responsibilities that the family already undertakes, and said that they would not choose direct funding if it were an option made available to them. For it to work, assistance regarding direct funding would be needed:

- **Caregiver training and quality assurance** to ensure that workers are professional, trustworthy and respectful.
- **Support/training for families** so that they can properly manage the responsibilities associated with being an employer.

There was concern expressed by some families that direct funding, single point access, and independent planning would create a layer of bureaucracy, which would reduce the amount of funding available for the individual, as well as potentially duplicating services.



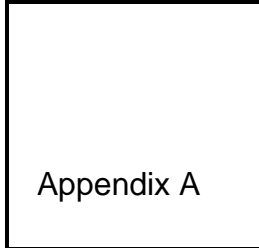


## In Conclusion

*Opportunities and Action* gave anyone with an interest in the future of Ontario's developmental services a venue to share their thoughts and feedback as the government develops a long-term plan to create an accessible, fair and sustainable system of community-based supports that will help people with a developmental disability realize their potential.

The consultations clearly revealed that there is no single solution to the diversity of needs, and as a result, there needs to be considerable flexibility and choice built into the system to allow families and agencies to tailor service delivery models. For example, many families welcomed the opportunity for *increased choice* and more control over services which would allow flexibility to choose a more independent family-focussed service delivery model. But many other families preferred to address their needs by working in partnership with an experienced agency.

Every individual who has a developmental disability, family member, service provider, advocate and community member that participated in the *Opportunities and Action* consultation and the overall transformation process has made an important contribution to the vision of a stronger system of supports for Ontarians with a developmental disability. The input that was received provides valuable insights on current supports and important ideas for the future.



## List of Family Consultation Meetings and Locations

Date	Location
Wednesday, May 24	Peterborough
Wednesday, May 24	Newmarket
Thursday, May 25	Oshawa
Monday, May 29	North Bay
Tuesday, May 30	Sudbury (English)
Tuesday, May 30	Sudbury (French)
Wednesday, May 31	Cambridge
Thursday, June 1	Hamilton
Monday, June 5	Toronto – meeting #1 (Scarborough)
Monday, June 5	Toronto – meeting #2 (Central Toronto)
Wednesday, June 7	Ottawa (English)
Thursday, June 8	Ottawa (French)
Monday, June 12	Thunder Bay
Tuesday, June 13	Sault Ste. Marie
Wednesday, June 14	Timmins
Wednesday, June 14	Mississauga
Thursday, June 15	St. Catharines
Thursday, June 15	Kapuskasing (French)
Monday, June 19	Kingston
Tuesday, June 20	Owen Sound
Wednesday, June 21	Windsor
Thursday, June 22	London – meeting #1
Thursday, June 22	London – meeting #2
Wednesday, July 12	Dryden

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