

**Services for Children and Youth with Special Needs
in Ontario, and their Families:
*Opportunities for Improving their
Experiences and Outcomes***

**Advice to Minister Piruzza
Minister of Children and Youth Services
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Minister of Children and Youth Services**

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Table of Contents

FOREWORD	3
SECTION 1: INTRODUCTION AND BACKGROUND	5
Introduction	5
Background	6
SECTION 2: SCOPE	7
2.1 Access to information and services	7
2.2 Assessment	7
2.3 Transitions between services and to adult services	8
2.4 Respite	8
SECTION 3: METHODOLOGY	9
3.1 Format of the engagement meetings	9
3.2 Meetings with provincial family and provider associations	9
3.3 Regional meetings with families and providers	9
3.4 Meeting with researchers	10
3.5 Demonstration of a provincial system of shared electronic files and community health portal	10
3.6 Written submissions	10
SECTION 4: SUMMARY OF STAKEHOLDER FEEDBACK AND ADVICE FOR IMPROVING THE EXPERIENCES OF CHILDREN AND YOUTH WITH SPECIAL NEEDS, AND THEIR FAMILIES	11
Access to information and services	11
Assessment	16
Transitions between services and to adult services	18
Respite	25
Appendix A: Participants at the Meetings	28
Appendix B: Discussion Guide for Meetings with Families	31
Appendix C: Discussion Guide for Meetings with Associations, Service Providers and Researchers	33
Appendix D: Summary of written submissions received	35

FOREWORD

While Parliamentary Assistant to the Minister of Children and Youth Services I had the opportunity to serve two Ministers: the Honourable Eric Hoskins and the Honourable Laurel Broten. In this role I led an engagement with families, service providers, provincial associations and researchers to discuss opportunities for improving experiences for children and youth with special needs in Ontario.

I undertook this engagement for two reasons. First, Minister Hoskins asked me to engage with families of children and youth with special needs when he became aware of the complexity of services and the barriers faced by families with children and youth who have special needs through letters and feedback from families, service providers, and researchers as well as working with other ministries that have responsibilities in this area. When Minister Broten became Minister of Children and Youth Services she continued to support this initiative, and now it is my pleasure to submit this report to the Honourable Teresa Piruzza, the current Minister of Children and Youth Services.

Secondly, I have a long-standing interest in the disability sector. As a mother of a child with special needs, I know firsthand the challenges faced by families trying to access information and navigate through various agencies and service providers. The experiences families shared with me during this engagement brought me back to a time not long ago when I was contacting friends and service providers, attempting to figure out who to talk to and where to go to get help for one of my premature twins.

I had considered myself reasonably knowledgeable about the disability sector through my personal experience in addition to my previous career in human resources that focused on human rights and discrimination prevention. However, the reality was different. I was beginning a long journey on an unknown route of appointments, assessments and coordination of services and transitions for my son.

My goal was to advocate for my son while balancing the needs of my entire family and also trying to look after my personal and professional goals. I began volunteering with initiatives that supported the inclusion of people with disabilities and the removal of barriers. I became a member and then ultimately Chair of Ontario Accessibility Standards Advisory Council, which had a mandate to advise the Minister of Community and Social Services on the implementation of the Accessibility for Ontarians with Disabilities Act. As well, one of my most rewarding volunteer activities for many years, until early 2013, was as a member of the Special Education Advisory Committee at my children's local school board.

I am not alone in these efforts. Numerous families I have talked with have also gone above and beyond the care of their child with special needs and their own family by engaging in activities that will help other families and children with special needs such as participation in parent networks, and volunteering with groups focused on supporting children with special needs. These families have done this all while trying to balance their own family, personal and professional needs. Their experiences have been a significant catalyst for this report.

This report includes my advice related to simplifying access to information and services, streamlining the assessment process and building more seamless transitions; and supporting families with effective respite services. This report is the product of the engagement meetings and also draws from many recommendations from other work noted in Appendix D. I was pleased to hear the success stories and

best practices highlighted in this report and they affirm that we do not need to start from scratch to improve the service experiences and outcomes of children and youth with special needs in Ontario.

There is a real opportunity for the Ministry of Children and Youth Services to initiate a project to provide system oversight and strategic management of the advice in this report. While there are many excellent initiatives and best practices in place by service providers and agencies, the need to have success across the province and to take a more systematic approach is palpable throughout the sector and from the voices of families with children and youth who have special needs.

It has been my privilege to meet with families from across Ontario as well as service providers, associations and leading researchers in the field of children with special needs – a total of 117 different people and many organizations – to hear their experiences and recommendations.

I would like to take this opportunity to acknowledge and give my personal thanks to each participant for generously contributing their time and information to this engagement process. The moving and heartfelt quotes in this report are a small sample of the personal challenges and concerns the participants shared with me. I would also like to thank the staff at the Ministry of Children and Youth Services who assisted me with this project.

Tracy MacCharles, MPP
Minister of Consumer Affairs

SECTION 1: INTRODUCTION AND BACKGROUND

Introduction

The Ministry of Children and Youth Services was created in 2003 to bring more focus to the needs of children, youth and their families by providing the most valuable, cost-effective services and supports to help build a strong, healthy, resilient population of young people. This ministry envisions an Ontario where all children and youth have the best opportunity to succeed and reach their full potential.

The ministry provides a range of services to children and youth with special needs – services essential to the lives of many families. In addition, these families are connected to other systems for education, health care, recreation and financial support to enable their children to achieve their full potential.

In the fall of 2012, as Parliamentary Assistant to the Minister of Children and Youth Services, I met with families, providers, associations and researchers to hear about families' experiences with services and how to make improvements to services for children and youth with special needs.

The engagement project was initiated to:

- Develop an understanding of families' experiences with services for their children with special needs as well as other stakeholders' understandings of families' experiences in the following areas: access, assessment, transitions and respite; and
- Identify, and provide advice to the Minister, regarding opportunities for improving the service experiences and outcomes of children and youth with special needs in the four areas identified above.

The scope of the engagement did not include increased funding for services and was not focused on major transformation of the sector.

In developing a framework for this engagement, I consulted with Parliamentary Assistants from the Ministry of Community and Social Services, Ministry of Education, and Ministry of Health and Long-Term Care. They confirmed the project direction and provided input and participation where feasible.

From October 2012 through December 2012 the following engagement occurred: three meetings with provincial associations; meetings with families and meetings with providers in six Ontario regions (with seven regions represented); and, a meeting with researchers. I would have liked to visit each region however time did not permit an opportunity to meet with families and providers in the Eastern and Hamilton/Niagara regions. Invitees, as well as others who were unable to attend a meeting, were also invited to send a written submission.

The discussions identified opportunities outlined in this report for improving the service experiences and outcomes of families with children and youth with special needs in the areas of access, assessment, transitions and respite. This report provides a summary of the feedback and advice on how to move forward on improving the experiences and outcomes of children and youth with special needs in Ontario, and their families.

The families and providers who shared their experiences and insights have made this report possible; their contributions are deeply appreciated.

Background

Children and youth with special needs have challenges related to their physical disabilities, developmental disabilities, mental health disorders, behavioural issues, and/or chronic medical conditions.¹

It is difficult to know the exact number of children and youth receiving special needs services in Ontario because many of these children and youth have multiple needs and receive multiple services. These special needs may be one or more of a wide range of specific impairments and/or diagnoses including: behavioural issues, communication disorders, physical disabilities, cerebral palsy, acquired brain injuries, developmental disabilities, Down syndrome, spina bifida, autism spectrum disorders, mental health disorders and/or long-term medical conditions.

In Ontario, an estimated 97,000 to 235,000 children and youth have special needs.²

The Ministry of Children and Youth Services provides funding to over 500 transfer payment agencies to provide an array of programs that treat and support children with a range of special needs. Further, this ministry shares responsibility for children and youth with special needs with three other ministries: Community and Social Services, Health and Long-term Care, and Education.

The **Ministry of Children and Youth Services** funds:

- Rehabilitation services (e.g., speech-language pathology, occupational and physical therapy);
- Respite programs;
- Autism services;
- Early years programs (preschool speech -language pathology, infant hearing and blind low vision);
- Infant development program;
- Child and youth mental health services; and
- Residential services.

The **Ministry of Health and Long-Term Care** funds:

- Hospital-based acute care and chronic care;
- School health support services (nursing, personal support, speech and language pathology, occupational therapy and physical therapy);
- Nursing and other related home care services delivered through Community Care Access Centres (CCACs); and
- Assistive Devices Program and Trillium Drug Program (direct funding and benefits programs).

The **Ministry of Education** funds school boards to provide special education programs and services to students who have been identified as exceptional pupils.

The **Ministry of Community and Social Services** funds:

- Special Services at Home (direct funding program);
- Assistance for Children with Severe Disabilities (grant program); and
- Children's developmental services.

SECTION 2: SCOPE

As the Parliamentary Assistant for the Ministry of Children and Youth Services I met with families, service providers, researchers and provincial associations in a series of meetings in the fall of 2012 to collect feedback to identify opportunities to improve service delivery in the following four areas:

- Access to information and services;
- Assessment;
- Transitions between services and to adult services; and
- Respite.

The scope of the engagement did not include increased funding for services and was not focused on major transformation.

2.1 Access to information and services

Access relates to a family's ability to understand, locate and connect with the services their child requires.

Children and youth with special needs require specialized services and/or supports to enhance their health, development, and participation in activities at home, in school or in their communities. These services are funded through multiple sectors, including the ministries of Children and Youth Services, Health and Long-Term Care, Education, and Community and Social Services. The services and/or supports are delivered through a range of agencies, including children's treatment centres, children's mental health agencies, respite, developmental service agencies, schools, hospitals and public health units.

How families access services depends on their child's needs and the access and coordinating mechanisms available in their local communities. A diagnosis may be required to access some services in Ontario; exceptions include services provided by CCACs and school boards.

Access mechanisms in Ontario are single agencies or multiple agencies working in partnership within the community where families can make their first contact to find about receiving local services. The availability of local access mechanisms varies from community to community.

The process to attain services for their child once a family reaches an access mechanism usually includes intake, assessment, prioritization, referral and /or service provision. However, not all services are accessed through an access mechanism. Families can go directly to some services, such as respite, children's treatment centres and CCACs.

2.2 Assessment

Assessment refers to the process a service provider uses to identify and plan for a child's/family's individual service needs. Assessments may include: eligibility assessment (assessing whether a child/family is eligible for a specific service), needs assessment (assessing a child's/family's specific needs), assessing for service priority (to prioritize based on urgency/severity of need), risk assessment (e.g., safety), and assessing for the purpose of developing an individual service plan.

Due to multiple assessment and access points, some families report that they must repeat their story multiple times, to multiple providers. They also feel that the system is lacking a mechanism for information sharing between professions and disciplines, often leaving it up to the family to collect and share information about services their child may be receiving.

2.3 Transitions between services and to adult services

In this context, transitions refer to the child's and family's experience as they move from receiving one service to another, either as they age (e.g., pre-school to school-based services/supports; children's special needs services to adult services) or their service needs change.

Transitions can be stressful for families of children with special needs. Challenges include reassessments for new services at transition points, the experience of gaps in service when children are discharged from one service, the wait to be assessed, and then another wait for a new service to begin.

2.4 Respite

Respite services provide temporary breaks from caregiving for family caregivers of children and youth with special needs. They can also provide the child/youth with the opportunity to engage with adults and peers outside of family and to participate in meaningful activities.

Families of children and youth need respite services to: have a break from the day-to-day care of their child with special needs; look after the needs of other children in their family; support their own physical, emotional and social needs to avoid burn out; and, help parents and families stay together.

Respite, provided both at home and in other locations, can provide children with an opportunity to have social connections, engage in learning, and generalize the skills developed through other services.

The care that families provide for children and youth with special needs can be stressful, time consuming and complex. As more adolescents with serious conditions survive into adulthood, care giving needs are extending over many years, and in some cases, a lifetime.

Planned respite supports can help families improve resilience and the ability to cope with stress and can prevent crises.

SECTION 3: METHODOLOGY

3.1 Format of the engagement meetings

The engagement was formally launched in October 2012 and completed in December 2012. During this three-month period I met with provincial family and provider associations; hosted regional meetings with families; hosted regional meetings with providers; and met with researchers (see Appendix A).

Discussion guides were developed for the engagement meetings to provide a consistent framework for the conversation for each of the stakeholder groups (see Appendix B and Appendix C). Each group was asked questions related to accessing services, the assessment stage, transitions and respite.

3.2 Meetings with provincial family and provider associations

Family Alliance Ontario (three representatives) and Autism Ontario (one representative)
Ontario Association of Children's Rehabilitation Services (OACRS) (three representatives)
Ontario Association of Community Care Access Centres (OACCAC) (four representatives)

3.3 Regional meetings with families and providers

Two meetings, one with families and one with service providers, were held in five Ontario locations; and one meeting with families only was held in a sixth. The meeting participants were selected and identified through the regional offices using a consistent process.

Each regional office was asked to invite six to eight providers who serve children with special needs and are able to speak to some/all four topic areas (access, assessment, transitions and respite), e.g., children's treatment centres, CCACs, respite provider, access mechanism, service provider with experience with clients who require transition(s), autism service provider.

The regional offices worked with providers to invite six to eight families representing with a range of special needs, including a family having a child with medical complexities, a child served by a children's treatment centre, a child experiencing transitions, a child receiving in-home services and a child receiving school services, a member of a family network, a family member who could speak about respite, access, assessment processes; and, if possible, a family with rural and cultural needs.

Discussion guides were sent along with the invitations to the meetings. To encourage and support family participation the meetings were structured to be small in size to help families feel comfortable sharing their experiences. Necessary child care and travel expenses incurred by the family members to attend the meeting were also covered by the ministry.

Summary of Engagement Participants

Number of Participants*				
Region	Family Members	Providers	Association Representatives	Total
South West Region (London)	8	7	n/a	15
Central West Region (Guelph)	9	8	n/a	17
Northern / North East Region (Sudbury)	11	7	n/a	18
Eastern Region (Ottawa)	Anglophone 5 Francophone 7	Anglophone 11 Francophone n/a	n/a	23
Central East Region (Newmarket)	7	12	n/a	19
Toronto Region (Toronto)	7	n/a	12	19
Total	54	45	12	111

* Number of participants represents unique individuals and not unique organizations - some association representative organizations and one service provider organization were represented by more than one individual in a meeting.

3.4 Meeting with researchers

In addition, a meeting with six researchers and staff from McMaster *CanChild* and Holland Bloorview Kids Rehabilitation Hospital was held in Toronto.

3.5 Demonstration of a provincial system of shared electronic files and community health portal

The Ontario Association of Community Care Access Centres hosted a meeting to demonstrate its province-wide shared electronic files and community health portal.

3.6 Written submissions

Many informal and formal written submissions were provided by some of the families, providers, associations, researchers and other interested parties. See Appendix D for a list of the written submissions.

SECTION 4: SUMMARY OF STAKEHOLDER FEEDBACK AND ADVICE FOR IMPROVING THE EXPERIENCES OF CHILDREN AND YOUTH WITH SPECIAL NEEDS, AND THEIR FAMILIES

What we heard from families, providers, provincial associations and researchers about families' experiences with services:

Access to information and services

A. Families have difficulty finding accurate and up-to-date information about programs and services for children and youth with special needs.

Families said there is no obvious access point to information about services; their best source of information is other families of children with special needs. Many families expressed that they are solely responsible for finding information about services – agencies do not reach out to them nor do they promote their services adequately.

Families, providers, associations and researchers provided a wide range of ideas for how families can learn about programs and services for children and youth with special needs.

A single point of access was a consistent recommendation across the stakeholder groups. Families specifically said they want a single place to find online information that is accessible, accurate, and available 24 hours a day, seven days a week. Families want to search for information in their home after their children are in bed and there is no travel involved. Families often expressed that they want to be able to connect with other parents online.

Some families said their first “go to” source for information should be their physician, but they find physicians have a knowledge gap about community services. Many families suggest being linked with another parent to provide information and support after their child receives a diagnosis. Some providers suggested ‘buddying’ parents with other parents after the initial diagnosis and at the beginning of a transition.

One family suggested the creation of a service similar to Telehealth for the parents of children with special needs. Telehealth Ontario is a free, confidential telephone service to get health advice or general health information from a Registered Nurse.

Another family recommended creating a seamless system with known access points and one place for parents to go to with their questions. Some families noted children’s treatment centres helped them access services.

In the Northern Region the Children’s Community Network was identified as a central access mechanism that connects families to services. Providers pointed out commonly used access points including the Infant Development Program and children’s treatment centres. Most families were

“If you don’t know where to look or how to advocate for yourself, you could easily drown or never get the help.”

A parent in
Central East
Region

“The system needs to care for the whole family, not just the child.”

A provider in
Eastern Region

unaware that the role of CCACs includes information and referral to a wide range of services; and families receiving CCAC services reported varying degrees of satisfaction with how helpful the case managers were in providing information. Some providers noted that the 18-month well-baby visit is the best way to identify needs early. According to the researchers the best place to reach children in order to identify special needs, provide timely interventions, and begin transition planning is in school.

Families with children who have complex needs generally reported that they do not have as much difficulty accessing services given that there are well known/established agencies and service providers focusing on specialized service and programs.

B. Once families reach an access point, they have difficulty navigating the system to attain services.

The difficulty parents have navigating the system was raised by each of the groups of stakeholders.

The following point from a written submission about medically fragile children received from the Provincial Council for Maternal and Child Health reflects what was heard at the engagement meetings: “Families struggle to navigate a labyrinth of access points, process and rules in an attempt to cobble together supports and services⁴.”

“I have to hold my child’s hand through everything; I want someone to hold my hand.”

A parent in Eastern Region

A consistent recommended solution was also identified by parents and providers: the implementation of a system navigator to help parents “see the path” and link parents to information through a service pathway.

Some families emphasized that the navigator should not be provided through a service provider because the families want the navigator to be able to advocate for the family. Providers said that a navigator could help families by providing information about services they might need in the future (e.g., respite) to help prevent a crisis from developing.

Several families found their CCAC case managers helpful with navigation while other families found them unhelpful and bureaucratic. Many families saw the opportunity to create an online community for families to network with other families and develop their own mentor relationships. The possibility of a paid parent mentor in a navigator role to help parents on a short-term basis was discussed at several meetings. One agency in the South West Region helps match new families with parent mentors and this was described as beneficial to the parents and the agency.

“Think of a child as “of the system” rather than “of a particular agency” or “of a ministry.”

A provider in Central West Region

When trying to navigate the system families experience agencies and ministries operating in silos. Providers identified the need for inter-ministerial collaboration as a priority.

Parents and providers suggested that it would be helpful if there were central listings of local services where parents could search for services according to the type of service rather than according to agency name. One family saw an opportunity to create flow charts for physicians and families that would identify how and when to access services. Another family said hospitals should automatically offer assistance and basic navigation to families whose newborn spends time in the neonatal intensive care unit.

“It is unrealistic to expect parents to navigate the complicated system.”

A provider in Central East Region

Parents said they want to be given a system overview: a basic description of provider agencies, including what age range they serve and what services they provide. One parent said that Autism Ontario has a great booklet that helps guide families through the autism service system and it should be in every physician’s office.

Addressing language and cultural barriers was an important priority for families, associations and providers. (e.g., more services in French, the need for culturally appropriate services for Aboriginal children). In addition, in some regions the importance of service provision reflecting the cultural diversity of the community was stressed. The importance of providing information in a clear and simple way was emphasized by each stakeholder group.

C. Without a diagnosis many parents experience difficulty accessing services for their child.

Many families and providers said information and the process for accessing services should be focused around a child’s needs, not their diagnosis (or lack thereof). The researchers said that getting their child’s diagnosis does not automatically link a family to the appropriate services and that needing a diagnosis to access service can be “very distressing” for parents.

“Receiving services should be part of a plan; receiving services shouldn’t be by grace and good luck.”

A parent in Toronto Region

D. Families have concerns about wait lists.

Many families and providers expressed that once a child receives a diagnosis, the family then goes on other lengthy wait lists for services.

Many families and providers said wait lists lack transparency. Specifically, many families are not informed when their application has been received, or when it is under review, and they are not provided with an estimated timeline for a response to the application. Parents and providers also said families with multiple children with special needs should be the highest priority for services (i.e., not wait for services).

E. Families want support to access services quickly.

Families recommended that access to financial support should not be based on annual income. A family in Eastern Region said “you can make all the money in the world but if you’re spending it all on your child’s care you have no disposable income.” For example, several families expressed that there is not enough financial support for parents who have to travel to urban centers

“More intervention isn’t always better; it’s the timing and the focus that matters.”

A researcher

to obtain services because they experience additional costs related to mileage, parking, accommodation, and lost wages.

Providers and families noted that sometimes population-based funding is not adequate; for example, serving one child in a remote Northern community can carry as much cost as serving two children elsewhere in the province. As well, population-based funding does not always keep up with rapidly growing urban areas. Some providers and families noted a need to improve services for First Nations children on and off the reserve.

Providers noted that early access to accurate information about services, such as respite, will help prevent crises. Providers suggested including information about timelines for accessing services when providing information about services to families.

F. Families want services to emphasize the needs and strengths of the child and their family.

The researchers noted the “unit of interest should be the family.” Providers also said that service provision should be about the needs and strengths of the family as well as the child, not just a focus on the diagnosis – “If you don’t foster the strengths you’ll miss the prevention.”

Researchers also noted that services and assessments would be better if they were focused on the child’s social and physical environments, achievements and participation. Currently, the system is “a biomedical model” and focuses on a child’s deficits rather than strengths, development, and promoting his or her capacity.

“We’ve been trying to fix children we can’t fix rather than focusing on the child and what they can do”; “we don’t “fix” diabetics, we teach them how to live a satisfying life within the context of their disease.”

A researcher

SUCCESS STORIES

In **Central East Region**, agencies that provide services for children with Autism Spectrum Disorder formed a partnership that has a “**no wrong door**” philosophy, and partner organizations must commit to having their frontline staff participate in training. The partnership uses a “warm transfer” model: if a family ends up at the “wrong” access point, the intake worker gets their consent and helps them find the right access point.

Providers in **Central West Region** said the **Growing Great Kids System of Care** in their region (modeled after Simcoe York Children’s Treatment Network) is a great access point described as “one phone call”. The partner agencies have a memorandum of understanding about working together to provide comprehensive services.

A family in the **South West Region** reported that a **system navigator** helped them access three different services after telling their story once.

ACCESS TO INFORMATION AND SERVICES

ADVICE to improve the experience of families of children with special needs who require access to information and services:

Determine the feasibility of:

- 1.1 Implementing a cross-sectoral (children’s, health, education, and community-based services) on-line source of accurate, up-to-date information for families of children and youth with special needs. The website should be widely marketed throughout the sector as well as through physicians, CCACs and other health care providers and include:
 - provincial, regional, and locally-specific information about services and supports for children and youth with special needs
 - information about how to get a diagnostic assessment; and
 - chat rooms and discussion forums for families.
- 1.2 Mapping local cross-sectoral service pathways for children and youth with special needs and their families.
- 1.3 Providing navigation assistance (e.g., phone line, service navigator, care coordinator) for families who need assistance finding services. Consideration should be given to prioritizing navigational assistance to families in crisis, families new to Ontario and those families who would benefit from navigational support during key milestones (e.g., transitioning through phases of the school system and when transitioning between service providers).

Assessment

A. Families are frustrated telling the same story for multiple assessments, especially when the multiple assessments do not lead to any services.

Many families find children's service providers are not connected; each agency requires separate intake and assessments. Each of the stakeholder groups noted that families have to repeat their stories multiple times.

What families have expressed as particularly frustrating is the time involved in repeating assessment information for children with chronic, long-term conditions that are permanent and do not change.

While some assessments, such as those required if a child's needs are changing, can be necessary; providers noted that the assessment process could be significantly streamlined.

Another recommendation was to improve information sharing. Families and providers pointed out that shared electronic files and standardized assessments would reduce the number of times that families would need to tell their story and would link different parts of a child's support team.

One of the points of care that could be streamlined is when a child or youth transfers between agencies. Providers identified that having the transferring agency provide information to the receiving agency would eliminate the need for parents to repeat information.

Some families recommend using Individual Education Plans (IEP) to share information about services and programs the children use outside of school. However, researchers noted that clinicians find that most IEPs are very generic and do not address the functional problems the child is dealing with – "the comments section feels like it's just cut and paste from the last IEP."

Families also said that some private assessments are not accepted by school boards for inclusion in the development of the IEP, e.g., a school board may not allow a child's IEP to include behavioural management strategies outlined in the child's privately paid assessment.

The wide range of views about the purpose and effectiveness of IEPs is significant given that most children with special needs attend school either full or part time. Significant resources are invested in developing and updating the information in the IEP during a child's time at school. For example, in the IEP, information is provided about assessments (done within and, in some cases, outside the school board), strengths and weaknesses, student goals, accommodation and modifications.

Researchers said there are too many assessments for children with special needs. They discussed a resource developed in the 1990s by *CanChild* called Keeping it Together (KIT) that helps parents develop advocacy skills, keep information about their child, access information about services, etc.

"It would be helpful to engage service providers to develop a system where they honour another professional's assessments."

A parent in South West Region

"Not every child needs the same assessment. For example, a child with low needs requires a different assessment from a child with high needs"

A researcher

After using KIT, parents felt that providers were more responsive and their perception of the services they received improved.

The researchers pointed out that assessments should take into account needs that are based on the family's goals. Families and providers also emphasized the importance of a holistic assessment to address, in particular, the need for social inclusion in addition to the functional and medical needs.

B. Families are frustrated about having to complete numerous consent forms.

Families described being overwhelmed by the number of consent forms to sign. The importance of consent forms appeared different to families and providers. While providers expressed a strong emphasis on ensuring consent forms are signed, families were more concerned about obtaining the treatment for their child.

Many families were comfortable with electronic sharing of their child's assessments as long as initially there was a consent form that would indicate the sharing parameters between agencies.

C. Families want their child's needs to be assessed earlier so they are diagnosed and treated earlier.

Families said they really need to get a diagnosis when their child is young. One family's experience was that their school had a "wait and see approach" – whereby they consider kindergarten to be "observation years only" which further delays assessment and the child receiving services.

Providers expressed that teachers need training to identify children having difficulty meeting developmental milestones so that they can talk to the parents about the potential need for a diagnosis.

Some families said they felt forced to pay for private assessments rather than wait a long time for one through the school, and that many young and/or new parents cannot afford private assessments. Some families reported that some private assessments are not accepted by their child's school board. Researchers noted that this is a "huge problem".

The researchers felt that the many recommendations typically found in IEPs do not work in the classroom; they suggested that more focus needs to be on educating adults involved in the child's life about how to build on the child's strengths. The researchers also suggested that children should be assessed in "the real world" rather than in a clinical setting – this would help create more realistic interventions.

"We need to coach teachers on how to work with children with special needs. There is a significant amount of evidence on the benefits of coaching."

A researcher

SUCCESS STORIES

The researchers said **Growing Great Kids System of Care in Central West Region (Guelph)** is a good model for reducing the wait time for services as well as the number of assessments a child receives. Growing Great Kids System of Care is a partnership of organizations that makes it easier for families to access community services and supports for children up to age six. The partnership provides parents with many services, including:

- KIDS Line, a telephone line that provides answers to referral and child development questions; and
- Child Development Checklist, a tool for parents to assess their child's development that facilitates early detection and intervention for children with special needs.

Researchers recommended that providers use **point of care documentation** currently in place at **Holland Bloorview Kids Rehabilitation Hospital**. During a parent's meeting with the clinician, the parent checks the information the clinician is inputting on the child's assessment to ensure its accuracy.

A well-kept secret? A **case management system called CHRIS** (Client Health Related Information System) provides **Community Care Access Centre (CCAC) case managers** with a common system to enter and track patient information and services. CHRIS creates an electronic link to the many health care service providers delivering nursing and personal care for patients, including children and youth with special needs. Further, integrated with CHRIS are a set of **standardized electronic assessment tools** and a **consent tool**. The consent tool is the part of the client's health record where it is recorded that clients have given permission for the CCAC to collect, use and share their personal health information. A client identifies any restrictions on a person or organization that they do not wish to share their information with and these restrictions would be recorded in the consent. If a client withdraws their consent at any time it is recorded in this area as well.

ASSESSMENT

ADVICE to improve families' experience with the **assessment** process:

Determine the feasibility of:

- 2.1 Implementing common needs based assessment tools and shared electronic records that enable agencies from many service sectors to share information to eliminate unnecessary assessments.
- 2.2 Integrating information from community providers (e.g., community agencies, physicians, other health care providers) into the Individual Education Plan (IEP) so that the IEP includes comprehensive assessment information. Further review and analysis of the effectiveness of IEPs may be required before pursuing this recommendation.
- 2.3 Piloting models of cross-sectoral service planning for children and youth with special needs, including identifying and sharing best practices and how to move toward outcome-focused services.

Transitions between services and to adult services

A. The present process for transitioning from preschool to school is difficult for families.

The transition from preschool services to services that are provided while a child is in school can be difficult for families, especially when the child is discharged from preschool services and has to be assessed for new services. A provider noted a child may be getting multiple preschool services and the same services are not available when they enter the school system. Researchers reported that parents can feel let down when their child enters school because they receive fewer supports at school than they received when their child was preschool. Families from Central West Region pointed out that KidsAbility provides a good transition from preschool to grade one.

A provider said that when a children's treatment centre does not have the contract to deliver rehabilitation services in a child's school, the child could still benefit from the children's treatment centre talking to the child's teacher to help manage the transition in the short term.

"Create a seamless system for persons with special needs rather than separate services for children and adults with special needs."

A parent in Eastern Region

B. The present process for transitioning from child/youth to adult services is difficult for families.

Families expressed that transitions put stress on families. They do not know what to expect when a child turns 18 and when he or she leaves high school. One family expressed that services to support youth transitioning to adulthood are the most needed but that this is the weakest point in the system.

There is confusion as to why there is an assessment process for youth with disabilities seeking adult services when there are no adult services available.

A family said the transition into adult services is feared, noting "there is no transition because there are no services."

Families feel that they have to start over again when their child turns 18. They want information automatically transferred from children's to adult services. One family stated "My child won't be cured when they turn 18." The system changes at this age, however, their needs have not changed.

Developmental Services Ontario (DSO) offices were introduced in 2011 with a mandate to provide a new single window to adult developmental services. DSOs provide information about community programs and resources, and determine what services and supports people need, confirm if they are eligible and connect people to specific programs.

"Eighteen-year-olds do not belong in a nursing home."

A parent in Toronto Region

"The 18th birthday of my daughter changes nothing – she still has the same needs at 18 as she did when she was two."

A parent in Toronto Region

Families universally reported that beginning April 2013 they are anticipating that there will be a long and unacceptable time lag between losing children’s Special Services at Home funding and receiving adult Passport funding through a DSO. They are expecting that, after initially applying to a DSO, they will have to wait to receive a response letter from the DSO, then wait for the mandatory assessment and then wait for Passport funding for which they stated there is no transparent wait list information.

When families apply for DSO services, an assessment by a psychologist is required. Because of the wait lists for such assessments and/or the costs associated with getting private assessments, some families are turning to school boards to conduct the assessments even though assessments provided through school boards are generally backlogged and school boards are not mandated or funded to conduct assessments for adult services. Some families also reported paying for expensive assessments and then finding out that the wait time for adult programs such as Passport may be many years.

There were also reports that families have been told by a DSO to pay for support services through Ontario Disability Support Program (ODSP) funds which families perceive to be actually intended for housing, food, and basic personal expenses.

C. Parents are concerned about aging and their long-term capacity to care for their adult child.

Parents want a “cradle to grave system” for respite. (i.e., support for parents caring for their adult children). Many parents want information and support in order to have a plan in place for their child’s care in the event that their child outlives them. Some parents found it too stressful or were too busy caring for their child’s current needs to begin planning for their child’s future care. Without a workable plan for their child’s future, many families emphasized that the future cost of their child’s care, e.g., in some cases unnecessary admissions to long-term care facilities, would put more of a financial and health care burden on taxpayers than selective home supports and good transition planning.

“When we die, what is in the cards for them [our children]?”

A parent in Central East Region

Parents expressed concern that as their child ages, fewer services are available.

D. The continuity of service during transition to other services needs to be improved.

Families expressed difficulty with access to services and wait lists when they moved or the child/youth changed schools.

A family noted, “In a perfect world the Individual Education Plan would guide all of a child’s care because the child is at school day to day.” Another family noted that electronic shared records between agencies would eliminate “carrying around binders” and worries about forgetting to provide key information. Electronic records would decrease duplication.

“As age increases the needs increase; as age increases the services decrease.”

A parent in Northern Region

Providers expressed frustration with the reactive versus proactive approach in the current system. As a provider in Central East Region explained, “We don’t

plan, we do crisis management.”

Providers noted transitions to school can be difficult when a child requires rehabilitation services as some children’s treatment centres discharge children from services when they enter school because School Health Professional Support Services, provided through CCACs, are mandated to provide rehabilitation services to children while they are in school. Children may need to be reassessed to receive services in school and may experience a wait before they receive services.

Providers explained that in some areas, such as Windsor and North Bay, there is a good relationship between the CCAC and children’s treatment centre, which helps streamline the transition into school, but that collaboration between children’s treatment centres and CCACs varies across the province.

Providers noted that it is difficult for medically fragile/complex children to move to and from hospital. Simcoe York children’s treatment centre benefits from a project funded by the Local Health Integration Network, in which there is a nurse navigator from the Hospital for Sick Children who coordinates multiple services. It also has an on-site clinic and telemedicine. This project was identified as a very good model.

Researchers emphasised the need to bring adult service providers “to the table” to improve transition planning. There are services for children designed to meet the needs of childhood-onset conditions, and often the same expertise is not available when the young person has to transition to adult services.

Providers also said teens with moderate needs have difficulty accessing post-secondary education; Carleton University was identified as a good model for transition supports.

SUCCESS STORIES

In the **Northern Region** providers described several success stories, including: CCAC rehabilitation staff working at the children's treatment centre so that they can treat the child in the children's treatment centre and continue their treatment when the child enters school; a successful transition to school model in Sudbury where the CCAC notes are used in the Individual Education Plan; and children in the preschool speech and language program are transitioning successfully into school.

There were several success stories reported in **Central West Region**: A family noted good transition from preschool to grade one through **KidsAbility**, which provided one point of contact and a transitions package; **Halton** has a successful cross-ministry and cross-agency planning table for children aged five and older who have special needs; and **Connections for Students** was also reported as a collaborative service model available across the province that is a successful initiative between the Ministry of Children and Youth Services and the Ministry of Education to help children with Autism Spectrum Disorder. In each region there are multidisciplinary transition teams to support children transitioning from the Autism Intervention Program to school.

Partnering for Change (P4C) is an innovative school-based intervention for children with Developmental Coordination Disorder developed by an interdisciplinary team at *CanChild*. Eight occupational therapists worked in school settings during the 2009/2010 school year to build capacity through collaboration and coaching, approaching the school as the "client," rather than individual students. This pilot was a partnership between the Mississauga Halton CCAC and *CanChild* as part of the CCAC's School Health Professional Services Program that provides a range of services, including occupational therapy, to enable children to attend school. Over 2,600 students and 160 teachers in 11 elementary schools participated in the pilot. Results from questionnaires and individual interviews indicated that this model was highly successful in increasing knowledge and capacity. P4C intervention holds promise for transforming service delivery in schools, and may be applicable with other populations of children, i.e., beyond the population of children with low needs who have been the focus of the studies thus far.

The **Toronto Central CCAC**, the **Holland Bloorview Kids Rehabilitation Hospital** and the **Hospital for Sick Children** have collaboratively developed the **Integrated Complex Care Model (ICCM)** for children with medical complexity. The overarching goals of the ICCM are:

- Improved cooperation between organizations;
- Better coordination across settings and levels of care;
- Greater focus on children's health needs as opposed to medical conditions;
- Maximized accessibility and minimized duplication of services and resources; and
- Enhanced outcomes for children with complex, chronic conditions.

The ICCM is formulated around the concept of a key worker dyad, partnered with the family unit to form a triad of care around children with medical complexity and their families. Together, the Clinical Key Worker (Nurse Practitioner) who has a prominent focus on clinical needs and the System Key Worker (CCAC Care Coordinator) who concentrates primarily on the 'system' needs including community resources and intensive case management, provide a single point of entry for children into acute care, rehabilitative care or community-based care settings, based on the immediate needs of the child and the child's family.

TRANSITIONS BETWEEN SERVICES AND TO ADULT SERVICES

ADVICE to improve the experience of children and youth with special needs **transitioning** through services and to the adult system.

Determine the feasibility of:

- 3.1 Establishing a process between community agencies serving young children with special needs and school boards for identifying and planning for the needs of individual children with special needs transitioning to Full-Day Kindergarten.
- 3.2 Establishing collaborative partnerships among school boards, community agencies and health care providers to facilitate successful transitions into and through school.
- 3.3 Implementing integrated cross-sectoral (MCYS, MCSS, MOHLTC, EDU, TCU) transition planning protocols for all young people with special needs preparing to transition to adulthood. Transition planning should begin at age 14, and incorporate information for parents about planning for their child's future care.
- 3.4 Implementing educational and training programs designed to increase cross-sectoral (e.g., health care providers, community agencies, educators) knowledge of the lifespan needs of adults with congenital or childhood-onset disabilities.
- 3.5 Initiating a priority review to examine the transition issues between provincially funded services and the associated wait lists and assessment requirements to move to adult services.

Respite

A. Families feel that respite is vital.

Both families and providers expressed concern that families do not receive enough respite; however, it was a much greater concern for families. The Holland Bloorview Family Advisory Committee identified respite as the most pressing priority for improvement.

Families and providers have identified that there are not enough workers qualified to deliver respite to children with high needs. Families find the high turnover of respite workers a great concern: one family had 19 different respite workers in five years.

“Respite is sanity.”

A parent in South West Region

Provision of in-home services through the CCAC (e.g., shift nursing) can provide respite for families, especially during the night. However, it was families’ experience that getting specialized overnight nursing care was very difficult.

Many families say they would rather care for their child themselves with respite support rather than have their child go to a group home. In Central West Region, three families asked to relinquish care of their child with special needs and stated that only this crisis brought long-awaited services.

Families expressed that because they had no respite they had lost friends, experienced marital breakdown, and had less time with other family members.

Many families talked strongly about the need for:

- simplified access to respite;
- both in-home and out-of-home respite options;
- planned, regular respite;
- consistency between regions so that when families move they do not lose their respite support;
- funding for crisis respite; and
- priority access to respite for families with multiple children with special needs.

“The whole family has special needs.”

A parent in Central West Region

B. School is a form of respite for families

Schools provide a valuable form of respite for families of children with special needs. When a child leaves the school system and is not connected to adult daytime activities (e.g., post-secondary education, day program), the family’s need for respite increases significantly, resulting in a crisis for many families.

To manage this transition, some families quit their jobs and/or re-mortgage their homes to afford respite care for their child with special needs, until they are no longer able to care for their adult child at home and feel they must turn to residential care for their adult child.

While school is a form of respite, families stated that students with special needs are often targets for bullying. Several families identified that schools need to be both more proactive about preventing bullying and more responsive when a student with special needs is bullied.

Many families said school principals have the most influence on a school's attitude and response to bullying. Some families reported that school staff, led by the principal, worked hard to engage students and managed to decrease bullying – “the principal sets the tone.”

Three families in one region reported that their child was bullied by school staff; including a principal and teachers (one family contacted the police).

“No one checks in with families to see how they are doing – families must always reach out for respite.”

A provider in Eastern Region

C. Some families need support to ask for respite before there is a crisis.

Several families expressed feeling “judged” and guilty for requesting respite services. When this feedback was discussed with the researchers, they said that the way in which a family is offered respite services can make a significant difference in a parent's willingness and/or comfort to use the service. For example, simply noting that respite provides a break from the child's *care*, not the child, reduces the guilt some parents feel about seeking respite services.

An article provided by *CanChild* researchers suggests some caregivers do not feel they have a right to ask for support from other families or from the community.³ The publication outlines the following advice to support families' needs for respite care:

- Families should attempt to understand and feel empowered to access supports (formal and informal) to help maintain their own physical and mental health.
- Service providers should inform families of the increased beneficial effect of respite services and encourage all health care providers to increase information provision to families regarding respite services in their community, especially to families with children who have lower levels of functioning and multiple medical conditions.
- Service providers should also strive to target respite information to caregivers with less well-developed informal supports.
- Service providers should ensure the continued competence of respite workers and quality service provision through continued worker training programs, the provision of competitive wages, by increasing accountability through continual quality assessments (yearly evaluations) of their services, and by including all family members in family-centred decision-making.

D. The caregiving responsibilities of families have substantially increased

Research articles about respite highlight the growing responsibilities of families. This reflects what was heard during the meetings with families. Children and youth with special needs often require care for a longer period of time and the medical and/or mental conditions that require the family's attention are often complex. Further, the care a family provides at home is without the resources typically available within hospitals. Financial burden is an additional stress for these families.

SUCCESS STORY

The **eShift** project is an initiative that leverages technology to provide enhanced support to children in a way that makes better use of human resources, through collaboration between the **South West CCAC and several partners**. Finding specialized pediatric nurses to provide one-on-one overnight care for children with medical complexity has historically been a challenge. The eShift initiative connects an enhanced-skill Personal Support Worker (PSW) at the child's home with an off-site registered nurse via a web-enabled iPhone. PSWs and nurses use the device to share information securely through a web portal. The software developed for the project is intuitive and includes highly customizable clinical decision support tools, a reference library, chat and phone capability, and supplies ordering features. Instead of working one-on-one with clients, eShift enables each pediatric registered nurse to monitor, mentor and manage care at up to four locations simultaneously.

RESPIRE

ADVICE to improve the experience of families seeking **respite** services:

Determine the feasibility of:

- 4.1 Establishing a continuum of respite services (offering a range of respite options) that is responsive to the individual and fluctuating needs of families and allows for planned regular respite as well as emergency respite.
- 4.2 Implementing transparent centralized regional wait lists for respite services.
- 4.3 Developing a provincial, evidence-based child and youth respite provider training strategy to promote consistent quality of care.
- 4.4 Establishing a protocol to promote consistency in the allocation of respite services to families who move from one region to another.
- 4.5 Developing and implementing provincially-consistent, cross-sector prioritization criteria and processes for the allocation of respite services to families.

Appendix A: Participants at the Meetings

South West Region (London) – October 30, 2012

Meeting with parents:

- 8 parents attended.
- The children ranged in age from 3 to 17 years of age with a range of special needs, including some with multiple/complex needs.

Meeting with providers:

- 7 providers attended.
- South West Community Care Access Centre, St. Clair Child and Youth Centre, CPRI, Thames Valley Children's Centre, Community Services, Coordination Network, Huron Perth Centre for Children and Youth, and Vanier Children's Services.

Central West Region (Guelph) – November 7, 2012

Meeting with parents:

- 9 parents attended.
- The children ranged in age from 3 to 18 years of age with a range of special needs, including some with multiple/complex needs.
- All but one parent had children with complex special needs. Three parents had two children with complex special needs.

Meeting with providers:

- 8 providers attended.
- Hopewell Children's Homes, KidsAbility Centre for Child Development, ErinoakKids Centre for Treatment & Development, Community Living Burlington, Child Development & Resource Connection Peel, Peel Children's Aid Society, Trellis Mental Health & Developmental Services, and the Waterloo-Wellington CCAC.

Northern Region (Sudbury) – November 22, 2012 (including representatives from North East Region)

Meeting with parents:

- 11 family members attended (nine parents and two grandmothers).
- The children had a range of ages (from toddler to 19 years old) and a range of special needs (child requiring the Infant Development Program and rehabilitation services from the CTC, one child with severe autism, one adolescent with Asperger's, three children with medical complexity; four parents had two children with special needs).

Meeting with providers:

- 7 providers attended.
- Child and Community Resources, Children's Community Network, Nipissing Children's Aid Society, Infant Development Program, One Kids Place (CTC), Child and Family Centre, and the French school board.

Eastern Region (Ottawa) – November 27, 2012

Meeting with parents (Anglophone):

- 5 family members attended (one couple, one grandmother, one mother, one father).
- The children ranged in age from preschool to late teens; their needs are complex and they use a high level of a range of services.

Meeting with parents (Francophone):

- 7 family members attended (parents and a grandfather, four mothers).
- The children ranged in age from 2 to 17 years old, and a range of special needs (medically complex, autism, learning disabilities).

Meeting with providers:

- 11 providers attended.
- Ottawa Children's Treatment Centre, Ottawa Rotary Home, Autism Intervention Program, Family and Children's Services of Renfrew County, Coordinated Access Ottawa, Christian Horizons, Roger's House for Palliative Care, Children's Developmental Services for Stormont, Dundas, and Glengarry

Central East Region (Newmarket) - December 5, 2012

Meeting with parents:

- 7 family members attended (grandparents who care for their grandson, two sets of parents, and three mothers). One mother has two children with special needs.
- One family participated by videoconference.
- The children ranged in age from 5 to 22 years old, with a range of needs (severe autism, mental health, complex care needs, and developmental delay).

Meeting with providers:

- 12 providers attended (more than one representative from some agencies).
- 2 providers participated by videoconference.
- York Simcoe Treatment Centre, Grandview Treatment Centre, Community Living, Catulpa Community Support Services (CSS), Blue Hills Child and Family Services, Service Coordination for Children and Youth, North Simcoe Muskoka CCAC, TriCounty CSS (Transitional Youth Coordinator)

Toronto Region (Toronto) - December 10, 2012

Meeting with parents:

- 7 family members (mothers) attended. Two mothers have two children with special needs.
- The children ranged in age from 6 to 26 years old, with a range of needs (autism, mental health, complex care needs, developmental delay, one child has high needs and does not yet have a diagnosis).

Meeting with *CanChild* and Holland Bloorview Kids Rehabilitation Hospital - December 19, 2012

Participants:

- Dr. Cheryl Missiuna, Director, *CanChild* and Professor, School of Rehabilitation Science, McMaster University
- Dr. Peter Rosenbaum, Co-Founder, *CanChild* and Professor, Paediatrics, McMaster University
- Dr. Mary Law, Co-Founder, *CanChild* and Professor, School of Rehabilitation Science, McMaster University
- Dr. Golda Milo-Manson, VP, Medicine and Academic Affairs, Holland Bloorview Kids Rehabilitation Hospital
- Dr. Gillian King, Senior Scientist, Bloorview Research Institute
- Christa Haanstra, Chief of Communications and Public Affairs, Holland Bloorview Kids Rehabilitation Hospital

Meetings with Provincial Family and Provider Associations

Family Alliance Ontario (three representatives) and Autism Ontario (one representative)
Ontario Association of Children's Rehabilitation Services (OACRS) (three representatives)
Ontario Association of Community Care Access Centres (OACCAC) (four representatives)

Appendix B: Discussion Guide for Meetings with Families

Introduction

The Ministry of Children and Youth Services provides a range of services to children and youth with special needs. We know these services make a difference in the lives of many families.

The ministry has identified a number of priority areas where improvements can be made to provide children and youth with special needs and their families with a better service experience and improved outcomes. These include:

Access to information and services

Improving access to information on where and how to access services.
Improving how families access the right mix of services.

Assessment:

Reducing the number of intake assessments when multiple services across sectors are required.
Reducing the need for families to repeat their stories multiple times.

Transitions:

Providing seamless and supported transitions between programs and sectors.

A. Access

Access relates to a family's ability to understand, locate and connect with the services their child requires.

Some families have reported that they are faced with navigating a complicated and frustrating system with multiple access points and intake functions across multiple sectors. As a result, families have difficulty making the first point of contact with the service system, getting information and accessing the right mix of supports for their child with special needs.

In this context, "access" refers to:

- access to information – a family's ability to find information about relevant services;
- access to services – a family's ability to locate the required service and the ease with which they begin the intake process; and
- service navigation – the ease with which a family is able to navigate the mix of government funded special needs services and connect with the multiple services their child may require.

Questions

1. Where do you find information on services for children with special needs (e.g., Ministry website, friends/family, health-care provider, and teacher)?
2. What barriers, if any, have you faced to access service (e.g., location, being placed on a wait list, language barrier, complicated application process)?
3. Do you have specific suggestions on how access to information and services could be improved for families with children with special needs?

B. Assessment

Assessment refers to the process an agency/service provider uses to identify and plan for a child's/family's individual service needs.

Assessments may include:

- eligibility assessment;
- needs assessment for the child and/or family;
- assessing for service priority (to prioritize based on urgency/severity of need);
- risk assessment; and
- information for the purpose of developing an individual service plan.

Questions

1. What is your experience with the assessment process?
2. What could improve the assessment experience for children and youth and their families?

C. Transitions

Children and youth with special needs must transition between services and sectors at several points during their development.

Children and families may face disruptions in service continuity due to fragmented transition planning, differing program mandates and inconsistent service delivery models, and/or waitlists.

In this context, "transition" refers to the child's and family's experience as they move from receiving one service to another, either as they age (e.g., pre-school to school-based services/supports; children's special needs services to adult services) or as they face changes in their service needs.

Questions

1. Based on your experiences, what are typical challenges faced by children and youth and their families during times of transition (e.g., transition to a new service, transitions to school, high school, and adulthood)?
2. How do you think that children and youth and their families should be supported during times of transition?

D. Additional Questions

1. Respite

What has been your experience in looking for and receiving respite services?

What do you think about families receiving direct funding for respite services?

Please offer two to three recommendations for improvement in respite services that would make the most difference for families.

2. Priorities

What do you see as the most pressing priorities for improvement in services for children and youth with special needs and their families?

Please offer two to three recommendations for improvement that would make the most difference for families.

Appendix C:

Discussion Guide for Meetings with Associations, Service Providers and Researchers

Introduction

The Ministry of Children and Youth Services provides a range of services to children and youth with special needs. We know these services make a difference in the lives of many families.

The ministry has identified a number of priority areas where improvements can be made to provide children and youth with special needs and their families with a better service experience and improved outcomes. These include:

Access to information and services

- Improving access to information on where and how to access services.
- Improving how families access the right mix of services.

Assessment:

- Reducing the number of intake assessments when multiple services across sectors are required.
- Reducing the need for families to repeat their stories multiple times.

Transitions:

- Providing seamless and supported transitions between programs and sectors.

A. Access

Access relates to a family's ability to understand, locate and connect with the services their child requires.

Some families have reported that they are faced with navigating a complicated and often frustrating system with multiple access points and intake functions across multiple sectors. As a result, families often have difficulty making the first point of contact with the service system, getting information and accessing the right mix of supports for their child with special needs.

In this context, "access" refers to:

- access to information – a family's ability to find information about relevant services;
- access to services – a family's ability to locate the required service and the ease with which they begin the intake process; and
- service navigation – the ease with which a family is able to navigate the mix of government funded special needs services and connect with the multiple services their child may require.

Questions

1. What are your impressions of what families encounter when looking for information and services?
2. What are your perspectives regarding how families access multiple services?
3. Do you have specific suggestions on how access to information and services could be improved for families with children with special needs?

B. Assessment

Assessment refers to the process an agency/service provider uses to identify and plan for a child's/family's individual service needs.

Because of multiple assessment and access points, some families report that they must repeat their story multiple times, to multiple providers. They also feel that the system is lacking a mechanism for information sharing between professions and disciplines, often leaving it up to the family to collect and share information from other services their child may be receiving.

Assessments may include:

- eligibility assessment;
- needs assessment for the child and/or family;
- assessing for service priority (to prioritize based on urgency/severity of need);
- risk assessment; and
- information for the purpose of developing an individual service plan.

Questions

1. What are your perspectives regarding the assessment process?
2. What do you recommend in order to improve the assessment experience for children and youth and their families?

C. Transitions

Children and youth with special needs must transition between services and sectors at several points during their development.

Children and families may face disruptions in service continuity due to fragmented transition planning, differing program mandates and inconsistent service delivery models, and/or waitlists.

In this context, "transition" refers to the child's and family's experience as they move from receiving one service to another, either as they age (e.g., pre-school to school-based services/supports; children's special needs services to adult services) or as they face changes in their service needs.

Questions

1. How do you think that children and youth and their families can be best supported during times of transition?
2. What are typical challenges faced by children and youth and their families during times of transition (e.g., transition to a new service, transitions to school, high school, and adulthood)?

D. Additional Questions

1. Respite

- What are your impressions of families' experiences with respite services?
- What are your perspectives on families receiving direct funding for respite services?

2. Priorities

- What do you see as the most pressing priorities for improvement?
- Please offer two to three recommendations for improvement that would make the most difference in the service experience for families.

Appendix D: Summary of written submissions received

Families

- AC – Email
- Anonymous – Enhanced 18-Month Well Baby Visit – Resource Pathway, Region of Peel
- BC – Including letter to their MPP
- DC – Including NY Times article “The Autism Advantage”
- KS & DS – Email
- SJ – PA Engagement Discussion Guide with feedback in bullets under each heading
- HR – Email and a letter from the Eastern Regional Office regarding the writer’s SSAH application
- Holland Bloorview Family Advisory Committee PA Engagement Discussion Guide with feedback in bullets under each heading

Providers

- Children’s Treatment Network of Simcoe York – PA Discussion Guide with feedback
- Community Living Algoma – a discussion guide with feedback in bullets under each heading
- One Kids Place Children’s Treatment Centre, “Access, Assessment and Transition Experiences for Children and Youth with Special Needs.”
- The Developmental Service Network - Halliburton Kawartha Pine Ridge District, “Kids Count Too...: Social Inclusion for Children and Youth with Intellectual Disabilities,” 2011.

Associations

- Ontario Association of Children’s Rehabilitation Services, “Coordinating Services for Children and Youth with Special Needs,” December 2012.
- Ontario Association of Community Care Access Centres, “Caring for Children and Families: Response to the Engagement on Services for Children and Youth with Special Needs” and Power Point presentation with same information, November 2012.
- Provincial Council for Maternal and Child Health, “Pursuing the Possible: An Action Plan for Transforming the Experiences of Children and Youth who are Medically Fragile and/or Technology Dependent, January 2013.

Researchers

CanChild Centre for Childhood Disability Research, McMaster University

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Endnotes:

¹ Child and Family Services Act (1990)

² CanChild Centre for Childhood Disability Research at McMaster University in Hamilton estimates the prevalence of activity limitations associated with chronic conditions among children and youth to range between 3.3% and 8%, resulting in roughly 97,000 to 235,000 affected Ontario children per year (2006)

³ Damiani, G., Rosenbaum, P., Swinton, M., and Russell, D., "Frequency and determinants of formal respite service use among caregivers of children with cerebral palsy in Ontario," *Child: Care, Health & Development*, 2003

⁴ Provincial Council for Maternal and Child Health, "Pursuing the Possible: An Action Plan for Transforming the Experiences of Children and Youth who are Medically Fragile and/or Technology Dependent", January 2013