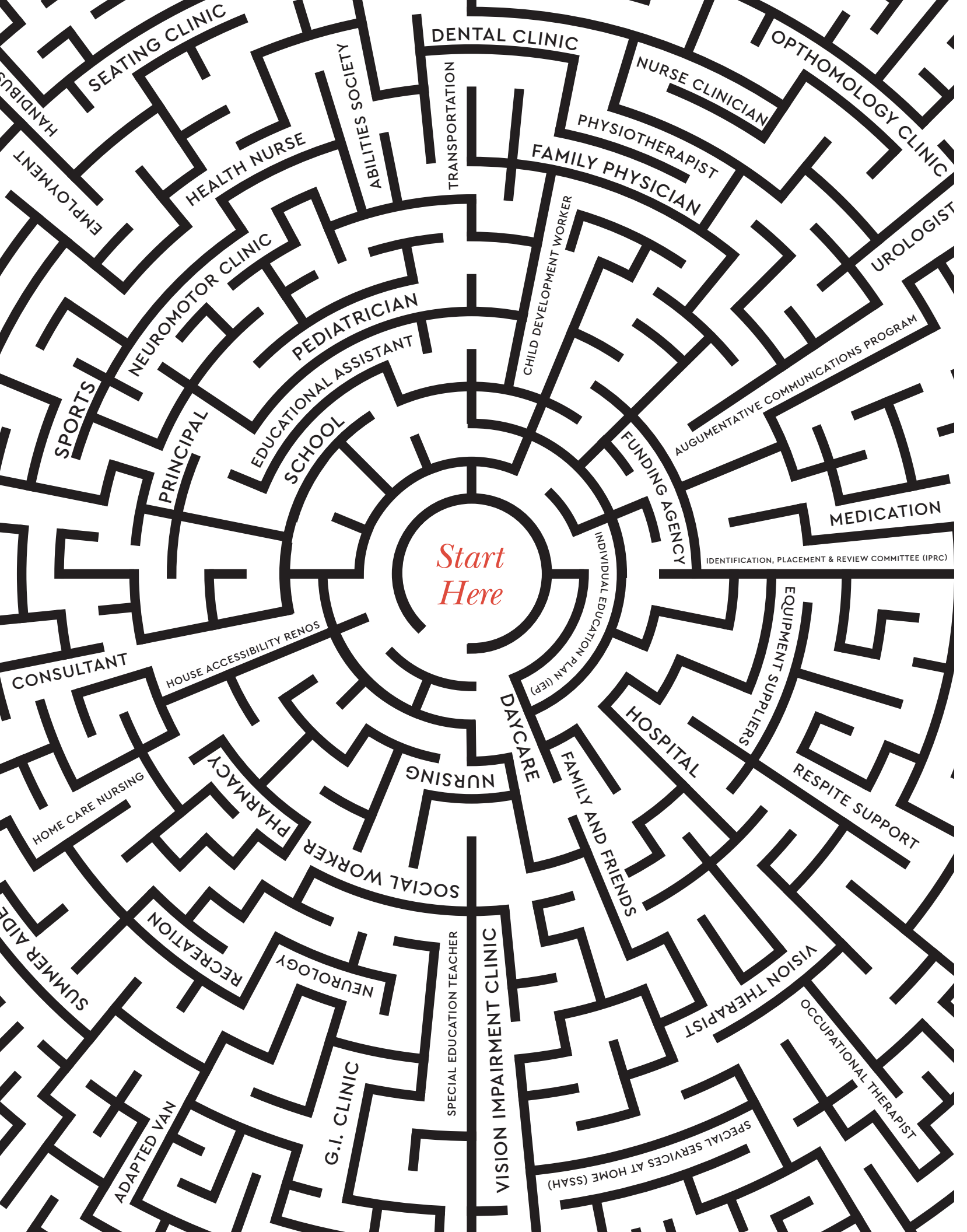


WE HAVE SOMETHING TO SAY

*Young people and
their families speak out about
special needs and change*





*Start
Here*

SEATING CLINIC

HANDICAP

EMPLOYMENT

HEALTH NURSE

ABILITIES SOCIETY

DENTAL CLINIC

TRANSPORTATION

NURSE CLINICIAN

OPHTHOLOGY CLINIC

PHYSIOTHERAPIST

FAMILY PHYSICIAN

UROLOGIST

AUGMENTATIVE COMMUNICATIONS PROGRAM

MEDICATION

IDENTIFICATION, PLACEMENT & REVIEW COMMITTEE (IPRC)

EQUIPMENT SUPPLIERS

RESPITE SUPPORT

VISION THERAPIST

OCCUPATIONAL THERAPIST

SPECIAL SERVICES AT HOME (SSAH)

VISION IMPAIRMENT CLINIC

SPECIAL EDUCATION TEACHER

G.I. CLINIC

ADAPTED VAN

SUMMER AIDE

RECREATION

NEUROLOGY

SOCIAL WORKER

PHARMACY

HOME CARE NURSING

CONSULTANT

HOUSE ACCESSIBILITY RENOS

DAYCARE

NURSING

FAMILY AND FRIENDS

HOSPITAL

FUNDING AGENCY

CHILD DEVELOPMENT WORKER

PEDIATRICIAN

EDUCATIONAL ASSISTANT

SCHOOL

PRINCIPAL

NEUROMOTOR CLINIC

SPORTS

WE HAVE SOMETHING TO SAY

*Young people and their families speak out
about special needs and change*

**Provincial Advocate
for Children & Youth**

ABOUT THE DESIGN

Children & youth with special needs in Ontario, along with their parents and caregivers, often compare their experiences of attempting to access services to navigating a maze. The young people whose voices are represented in this report want to have the same opportunities that other children and youth have to learn, form meaningful relationships, and pursue their own paths in life.

We Have Something to Say:

Young people and their families speak out about special needs and change

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978-1-987815-33-7

Nous avons quelque chose à dire : des jeunes et leurs familles s'expriment sur les besoins particuliers et le changement Numérique

978-1-987815-32-0

Nous avons quelque chose à dire : des jeunes et leurs familles s'expriment sur les besoins particuliers et le changement Livre imprimé

978-1-987815-31-3

We Have Something to Say: Young people and their families speak out about special needs and change Digital

978-1-987815-30-6

We Have Something to Say: Young people and their families speak out about special needs and change Book

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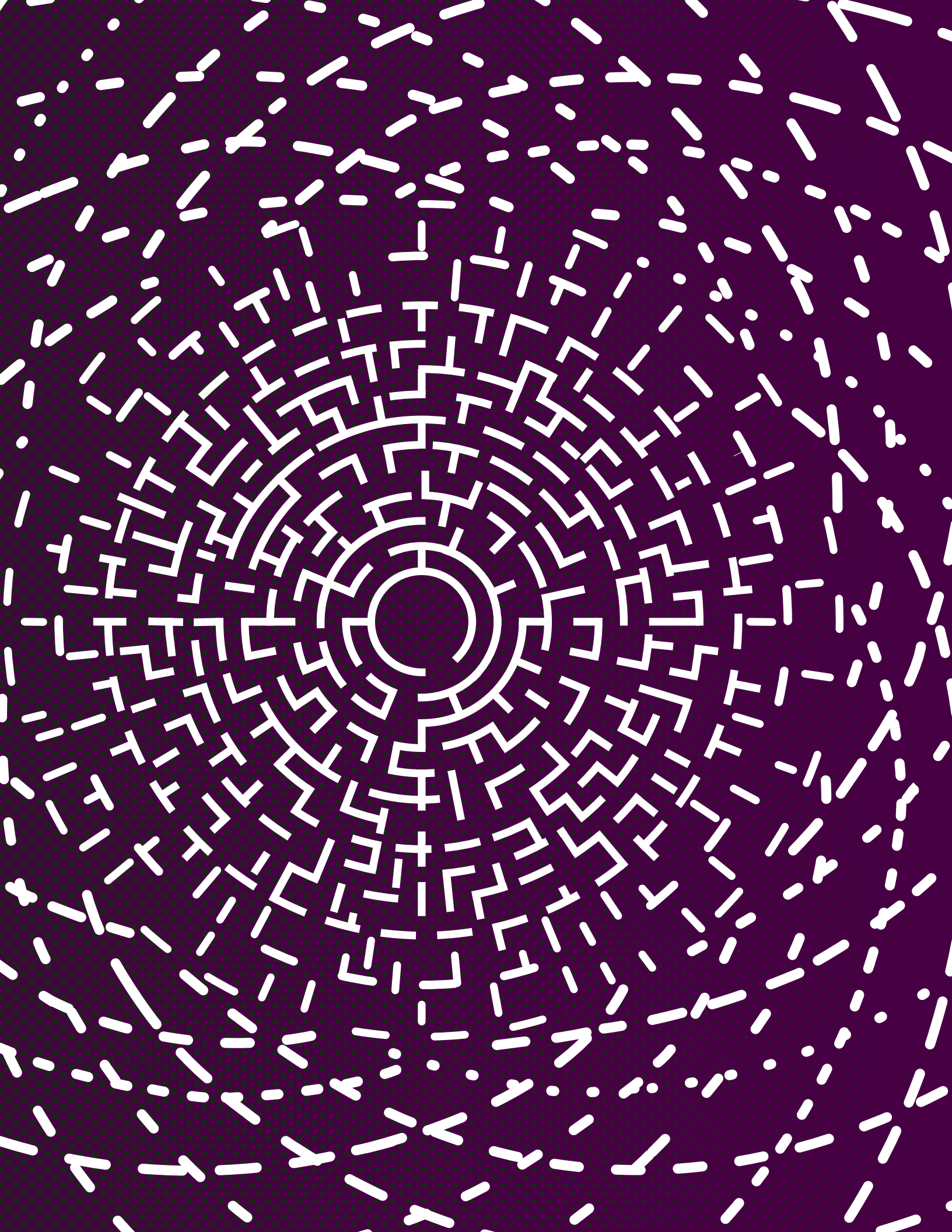


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the lifespan*

LETTER FROM THE ----- PROVINCIAL ADVOCATE -----

When asked what our Office does I have come to answer the question with something I heard from a young person. She said, “There are many strategies, action plans, frameworks, transformations, policies, laws, declaration of rights and lots of paper that have many nice words and great promises but then there is the lived experience of children and youth like me who are affected by all those words”. She continued, “There is a huge gap between what we are promised in all these words and our experience and that’s where your Office comes in. You help fill the gap with our voices in hopes of creating change”. I thought, ‘wow I wish I had said that.’

In taking on the work of mobilizing and elevating the voices of children and youth with “special needs” (a term used in our Act) I have come to the conclusion that in spite of all the fine words, paper, process and systems there are still far too many gaps between what exists and young people’s lived experience.

We have divisions in many of our ministries working to provide services and resources to children with special needs. The Ministry of Education for instance, is devoted to inclusion, special education and support services in one form or another. At the Board level we have similar departments and on the ground we have team meetings, IEPs, IPRCs, EAs, and a host of oth-

er acronyms that sometimes boggle the mind. And then we have a young person with cerebral palsy who said to me, “I used to think that school was supposed to be a mirror of what society could be, but what I found it to be was a mirror of what society is”. In that statement, filled with disappointment and a share of pain, she swept away all the fine words and said, “We can do better”.

When young people use their voices and name their world it takes a great deal of courage. But by speaking out young people with special needs make themselves visible. It is a risk, but for the young people we spoke with the wound of invisibility was a harm they no longer wished to endure. Hundreds, when given the opportunity, took the step of helping us produce this report. I thank them for their courage. I acknowledge their experience. I want to thank those young people who formed the strong and proud Advisory Committee that has carried “We Have Something to Say”. They have inspired and taught our Office a great deal. I know their work and report will teach and inspire the Province. They were once silenced, but never more. We will continue to be with you moving forward.

The young people are asking all those who have created the systems and written all those papers about them to listen. They are asking with respect while acknowledging that



there is no one with ill will who is trying to assist them. Listening takes courage too. Once we listen we cannot act as if we have not heard. We are left with the decision to reflect or not, to act or not, but we are changed by the act of listening. I ask the Province to listen to the children and youth whose voices are contained in the pages of this report. I ask the Province to join with them as they mobilize others to speak their truth. I am asking the Province to make change.

A handwritten signature in black ink, appearing to read 'I. Elman'.

Irwin Elman
PROVINCIAL ADVOCATE FOR
CHILDREN AND YOUTH

INTRODUCTION

The Office of the Provincial Advocate for Children and Youth takes on more than 300 individual requests for advocacy services every year from children and youth with ‘special needs’, children with a disability. The calls we receive come from young people and their families who typically are emotionally and physically exhausted and frustrated from dealing with complicated government programs and services. Young people may need testing or treatment or their family may need respite services. Some calls come from young people living in isolated or remote northern fly-in communities where they are forced to travel—or even permanently leave their homes and move—hundreds of miles from their communities to access the services and resources they need. In other cases we receive advocacy calls from parents who are newcomers whose child may have become ill after the family has settled in Canada and may have the added struggle of having a first language that is not English or French, making it harder to navigate services or know where to turn to for help.



A number of studies published in recent years indicate that the design and delivery of supports and services to young people with special needs in Ontario are in need of improvement: *Review of School Health Support Services—Final Report*, (2010)¹ and *Public Services For Ontarians: A Path To Sustainability And Excellence*, (2012)². While these studies have their limitations with respect to framing the issues, they nonetheless indicate that change in the system is needed urgently. In March of 2013, the government released its own report, *Services for Children and Youth with Special Needs in Ontario, and their Families: Opportunities for Improving their Experiences and Outcomes*³, based on meetings with families, service providers, associations and researchers in 6 regions of the province about how to improve services for children and youth with special needs. However, the scope of the meetings excluded discussion of increased funding for services or major transformation of the service sector. Also, the number of regions consulted was limited and excluded the voices and lived experiences of children and youth from Aboriginal communities in northern, remote and fly-in communities.

In the past eleven years the government of Ontario has introduced or passed legislation to improve services for persons with special needs. In June 2005, Ontario passed into law the *Accessibility for Ontarians with Disabilities Act* (AODA) to support the development of mandatory accessibility standards to identify, remove and prevent barriers for people with disabilities in key areas of daily living. The AODA builds on the *Ontarians with Disabilities Act, 2001* (ODA) that required the Ontario government and the private and broader public sector including municipalities, public transportation organizations, colleges and universities, hospitals and school boards to develop annual accessibility plans and make the province accessible to all Ontarians by 2025.

In February 2015, the Ministry of Children and Youth Services launched the Special Needs Strategy based on recommendations contained in the 2013 report men-

tioned above. Working together with the ministries of Education, Community and Social Services, and Health and Long-Term care, the province began conducting community engagement sessions to obtain ideas about how to create more integrated rehabilitation services and coordinated service planning for children and youth with special needs. We believe that the strategy holds promise if it can help improve the situation with respect to the availability and accessibility of services and simplify the processes involved in obtaining financial assistance, timely assessments, early intervention and other desperately needed supports, and ensure equitable provision of these new resources for young people across the province, particularly in remote or fly-in Aboriginal communities in Ontario's north.

In addition to the Special Needs Strategy, the province committed, in the 2014 budget, to investing \$810M to expand developmental services with \$200M over three years going to front-line workers in the community and developmental services sector. However, no new funding was allocated to base operating budgets of developmental services agencies, which will likely mean cuts to staffing, programs and services in order to cover the inflationary costs of operating these services.

The Partnership Council on Employment Opportunities for People with Disabilities was established by the government in April 2014 to support and encourage the hiring of people with special needs and to advise the Minister of Economic Development, Employment and Infrastructure about enhancing employment opportunities and removing barriers to jobs for Ontarians with special needs.

The above examples are not intended to provide a complete list or review of government initiatives to support children and youth with special needs. Such a review is beyond the scope of this project. What is important to note is that according to young people their needs are many and are often complex and that much more work needs to be done to ensure they receive the care and support to which they are entitled. Our greatest concern as an Office is not with any particular government initiative itself, but rather with the process. If young people with special needs and their families are not at the table as equal working partners with government and service

1. Source: Teloitte and Touche LLP. (2010). Review of School Health Support Services. Final Report.

2. Source: <http://www.fin.gov.on.ca/en/reformcommission/chapters/report.pdf>.

3. Source: <http://www.children.gov.on.ca/htdocs/English/documents/topics/specialneeds/PAreport.pdf>.

providers then there will continue to be gaps between policy, professional practice, service standards and the lived experiences of young people and their families. Young people with special needs require support and assistance and there is much that could be done to improve their lives without spending a single new dollar. They have knowledge and expertise to share and they want to be fully engaged and equal partners at every stage of the discussion and in the decisions that will have impact on their lives.

Bringing young people to the conversation with government and service providers

The Office of the Provincial Advocate for Children and Youth takes on more than 300 individual requests for advocacy services every year from children and youth with ‘special needs’, children with a disability. The calls we receive come from young people and their families who typically are emotionally and physically exhausted and frustrated from dealing with complicated government programs and services. Young people may need testing or treatment or their family may need respite services. Some calls come from young people living in isolated or remote northern fly-in communities where they are forced to travel — or even permanently leave their homes and move — hundreds of miles from their communities to access the services and resources they need. In other cases we receive advocacy calls from parents who are newcomers whose child may have become ill after the family has settled in Canada and may have the added struggle of having a first language that is not English or French making it harder to navigate services or know where to turn to for help.

To be eligible for some services and resources that a young person requires, they may need to go through a process of assessments or diagnostic testing. This often means ending up on lengthy wait lists because services

Defining “Special Need”

The term “special need” is difficult to define easily and can represent single or multiple needs faced by a person. The Ontario ministries of Children and Youth Services, Health and Long-term Care, Community and Social Services, and education use the following definition in the Special Needs Strategy:

Children and youth with special needs experience an array of challenges related to their physical, communication, intellectual, emotional, social and/or behavioural development. Children and youth with special needs may have needs in only one area of development such as language, or they may have needs across multiple areas.

Children and youth with special needs include children and youth who have a wide range of specific impairments and/or diagnoses including: communication disorders, physical disabilities, cerebral palsy, behavioural issues, acquired brain injuries, developmental disabilities, Down syndrome, spina bifida, Autism Spectrum Disorder, and chronic and/or long-term medical conditions.

The term “special need”, as it is used in this report, is the preferred term of the Youth Advisory Committee and subsumes all the needs identified by the provincial government in the definition above. Where the term “disability” appears in the text it is because it is used in a reference or a quote from a young person, family member or other contributor to the report.



that do testing can be expensive or are not available in some parts of the province. This is frustrating for young people and their families. Even when a young person has the required documentation that comes from diagnostic testing it doesn't mean they are automatically connected to the supports, services and treatments they require; they often end up on another wait list. This becomes part of navigating the service system as young people and their families have to continually retell their stories, repeat health information and explain why they need services. After a while they can begin to feel less like a child and family in need of support and more like a "client file".

Faced with the many challenges that can arise when trying to access any needed support services, life can become stressful and overwhelming for young people and their families. For example, parents who do not have access to the supports they need to help them meet the complex everyday health care needs of their child can lose the opportunity to just be "mom" or "dad" to their child. Without access to the funding for medical needs or other assistance their child requires, parents are forced to become medical caregivers, a role that deprives young people and their parents of an import-

ant emotional and nurturing connection. Parents' decision-making can start to become based more on managing risk or avoiding crisis situations and less on just being together as a family, doing the everyday things families do. Going to the park, to the movies, being part of community activities or even planning a family vacation get lost in the constant struggle to access services and resources that can help with addressing the needs of the young person that allow them to successfully take on the activities of daily living. What is often lost in the discussion of services, resources, assistive devices and medical equipment is that these resources are bridges to inclusion. They support the ability of the young person to be part of their community and community life. Without them young people and their families can become isolated in their homes and prevented from participating in all kinds of social activities like being in a classroom, going to camp, hanging out with friends and truly embracing the fun, excitement and reality of childhood and adolescence in a way that most children without special needs do. A lack of services and resources is part of a bigger conversation about social inclusion for all children in this province. It's not just a discussion about the service system, at its core it's about every child having the resources they need to em-

brace childhood, feel included and accepted and have a voice or say in their own lives.

A lack of resources and services has long-term effects on not just the young person, but their entire family. When parents are placed in the position of being the service provider for their children, the very heart of their role as a parent can change. This can impact the relationship between a child and their parents. As children grow into teenagers and want more independence from their families, parents may be reluctant to let them take risks or make their own decisions because they continue to see their son or daughter as being dependent. In many cases young people know their needs best and may start to resent parents making decisions about their lives or care without their input. The impact on families of not having needed services and resources in place can also affect relationships with sisters, brothers or extended family; the entire family can become strained when they are either called upon to take on the role of service provider or assist in helping the family manage. Siblings may feel parents are spending all their time, energy and resources on the child with special needs and may not want to add to their stress by talking about their own needs or issues.

Young people are, above all, individuals who have dreams and wishes for a life that is about more than a “diagnosis”. Young people tell us they want service providers to understand their unique situation and provide the supports that help them live the life they choose to live. Regardless of their “diagnosis”, they want service providers to be flexible and open to listening to them to find how to best meet their needs in any given setting — at home and school, while working, in recreation activities or out in the community. They also want service providers, parents and government to stop seeing “limitations” and holding them back from taking risks, trying new things and living life on their own terms.

Young people and their families often reflect that the social service system is full of gaps and the services and resources they receive depend on where they live and whether they happen to have access to effective and responsive case managers. Even with all this in place parents and young people are often put in the role of having to assess the specific training and skill of those helping them. In many cases, unless families or caregiv-

Estimates of the Number of Children with Special Needs in Ontario

It is difficult to know the exact number of children and youth that are receiving special needs services in Ontario because many of these young people 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. Estimates in Ontario range from 97,000 to 235,000 children and youth.¹

When it comes to special education, based on 2013–14 data from the Ontario School Information System (OnSIS), 334,312 students (16.6%) of the total provincial student population, from grades 1–12, were receiving special education programs and/or services. Of these 334,312 students, 194,697 (58%) were in elementary schools, and 139,615 (42%) were in secondary schools.²

In the most recent survey on population rates of disability among young people, 3.8% (83,600) of children and youth 0–14 years in Ontario were living with a disability that limited their daily activities.³

Approximately 1 in 5 children and youth in Ontario has a mental health challenge. About 70% of mental health challenges have their onset in childhood or youth.⁴

1. Source: <http://www.hpechildrenandyouth.ca/wp-content/uploads/2012/10/Special-Needs-Services-for-Children-and-Youth-with-Special-Needs-in-Ontario-and-their-Families-Tracy-McCharles-Report-March-2013.pdf>. pg. 6

2. Source: Ministry of Education (June, 2015). Special Education Update. Available online at https://www.edu.gov.on.ca/eng/general/elemsec/speced/SpecialEd_Update2015.pdf pg. 3.

3. Source: Statistics Canada. 2008. “Participation and Activity Limitation Survey of 2006: A Profile of Education for Children with Disabilities in Canada.” <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2008004-eng.htm>.

4. Source: <http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/mentalhealth/index.aspx>.



ers have the energy, financial resources or knowledge to get the system to respond to their child's needs, they may end up receiving or not receiving services they need.

Gaps in services make even the simple transitions of life very difficult as children grow up. Far too often they learn to “settle” instead of advocating for their needs to be met because they feel they do not have a voice or any control over their lives. As they move from hospital to home, home to school, from school to higher education, from school to employment, from institutional settings to community settings or from children's services to adult services, the message is the same: services are limited and, as such, their ability to claim their lives and the possibility of their dreams is limited.

We sometimes hear about success stories too — what we call “islands of hope” — where children are able to access appropriate assessments and obtain the funding, supports and services they need. It is possible for the system to get it right! Unfortunately, accessing proper care and support is the exception rather than the rule for young people with special needs in Ontario and these “islands” can sometimes disappear due to unstable political or economic factors that cause funding to run out.

Based on the many hundreds of calls we receive annually from young people with special needs and their

families frustrated with the gaps and barriers they encounter in the service system, we felt the time was right to bring their voices directly into a conversation with government, decision makers and service providers. We wanted to create a focused engagement process that would enable young people to share their lived experiences and ideas about what changes are needed in the system to ensure they receive the care and support they require to maintain their health, thrive and live their lives the way they choose.

Originally called, “I Have Something to Say” (IHSTS), the initiative began in late 2013. One of the first steps we took was to hire two Youth Amplifiers — Crystal Chin and Jonathan Robertshaw. They assisted the team by reaching out to community agencies, professional networks and youth and families who had contacted our Office for assistance to find young people who would be interested in participating on a youth advisory committee. In 2014, the committee began meeting regularly to support and inform the project work of IHSTS. There are now more than 30 members on the committee ranging in age from 8-30. Committee members are young people with a special need or who have lived experience within the community as a family member or sibling. In 2015, when the original Amplifiers left the Office, two new Youth Amplifiers — Holly Zhuang and Sammy D'Agostino joined the IHSTS team.

Since its formation, the IHSTS team has visited schools, organizations that provide services and resources to children and youth with special needs and their families, hospitals and community-based services. Numerous consultations and information sessions have been held to ensure the voices of young people with special needs were raised in every way possible. On December 3, 2014, the United Nations International Day of Persons with Disabilities, IHSTS provided a public information session on the experiences of young people with special needs at the University of Toronto. The event was live streamed. Children and youth with special needs who attended the event shared their stories about the challenges they face as a result of the service gaps that exist between government policy and their daily lived experience. Young people spoke about the unique barriers they face trying to find or access care. They also talked about what the IHSTS project means to them and what they hoped would change as a result of bringing forward the voices and experiences of young people with special needs.

The “We Have Something To Say” Project

In early 2014, IHSTS launched a project to bring together stories of young people with special needs. Through the IHSTS website and social media page the project team invited young people to participate in a discussion about their lived experiences and futures. We asked them to share with us what they thought would make a difference in their lives. We conducted outreach to young people and their families using emails to community partners, service networks, schools and the community, word of mouth and presentations at conferences. We invited young people to share their stories in the form of a “submission”—a video, personal note, poetry, written work, artwork, song or post to the IHSTS website or other social media. We also conducted 1:1 interviews with young people and invited family members, siblings, caregivers and professionals to make a submission based on their own experiences and ideas for change. By the end of December, 2014 we had received over 170 submissions.

The ratio of youth to adult submissions was approximately 50:50, a ratio not entirely surprising as many children and youth with special needs have difficulty com-

municating or lack access to the technology necessary to make their voices and wishes heard. Parents and families who made submissions spoke primarily on behalf of their children with special needs, but also raised issues they themselves faced dealing with schools, government and the service system. There were also a couple of contributions from service providers. It is important to note that this ratio of youth to parent submissions is reflective of the still large number of young people with special needs who remain voiceless and invisible and whose experiences need to be heard by government and service providers.

Once the deadline for making submissions was reached, the Youth Amplifiers began reading through the materials summarizing the issues of concern, common themes and recommendations for action to create change in the system. The Advisory Committee also contributed their experiences and recommendations for change. Members of the I Have Something to Say project team—Nikie Tentoglou and Janis Purdy—the Youth Amplifiers and the Advisory Committee worked to pull all of the information together in a draft report. Each chapter of the draft, along with the recommendations, was reviewed by the Advisory Committee, Amplifiers and the project team and their feedback and edits were incorporated into the final report. As the work of bringing together the voices represented in the submissions began to take form we noted we had moved from, “I Have Something to Say” to “We Have Something to Say”. “We Have Something to Say” is now the name of the initiative because it represents our mobilization as a community of individuals, families and allies wanting to be part of creating transformative change. For the purposes of writing this report and sharing the content with those who contributed their stories and other types of submissions under the initiative’s original name, we decided to use “I Have Something to Say” in the text.

Working on the project and reviewing the draft report was an emotional experience for the Youth Amplifiers and Advisory Committee members as it brought them face to face with their frustrations with government and services that, while sometimes helpful, continue to fall short of meeting their needs. They were also energized by the sense of community and purpose they found in working together to support each other and help prevent other young people from having to face the same barriers to supports and services. They were clear in wanting to be taken seriously by government and service providers and about wanting to be at the table in all policy and planning discussions regarding change in



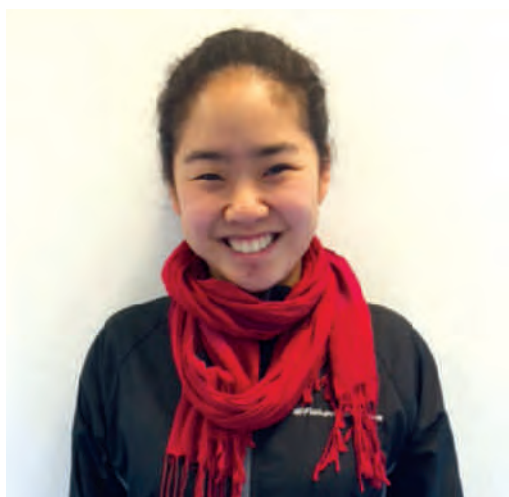
services to children and youth with special needs. They want action not words and they want to be involved as active and equal partners whenever decisions are being made about their lives. Until this fundamental change is made in the process of policy making and planning of services, young people will continue to feel like they are “outside of their own lives”. They will also continue to be excluded from full participation/social inclusion in the community or wider society by the continuing lack of accessible barrier free accommodation in education, employment and public spaces.

Only the beginning...

For ease of reading, this report has been divided into four primary chapters, each reflecting a setting in which young people, their families and caregivers identified gaps in services: Home and Family; School and Education; Supports and Services; and Transitions Across the Lifespan. The report represents the beginning of a conversation between young people, government and service providers. It is not intended as a complete picture of all the issues and concerns that children and youth with special needs face with the system nor does it reflect the experiences of all groups or communities of

young people with special needs. The report represents the experiences of those who responded to the call for submissions. The way issues or problems are described in the report and the way recommendations are made would be expanded if there was more representation from the transgender and LGBT communities, racialized young people, newcomers to Canada, Aboriginal youth and young people in care of the child welfare system for example. We believe as an Office that the issues raised in the report only touch the surface of the obstacles to service faced by young people and their families and need to be explored in greater depth in future projects. The Advocate’s Office wishes to extend its thanks to the young people, siblings and parents who opened their lives and shared their stories, experiences and ideas through submissions to I Have Something to Say. By your example you demonstrate the power of community coming together to help remove barriers to service, reduce the gaps between policy and practice and transform the system so that it better meets the needs of children and youth with special needs in Ontario. We also thank the organizations, community agencies and professionals who supported this work by passing along IHSTS’s contact information or sharing their thoughts about how to improve services to Ontario’s most vulnerable young citizens.

LETTER FROM THE YOUTH AMPLIFIERS



HOLLY



SAMMY

We Have Something to Say (WHSTS) is about actively listening to the voices of children and youth with special needs and having their life stories and voices heard by government and service providers. This work carries a lot of meaning and is dear to our hearts. Growing up we both faced many challenges with systems that were not responsive to our needs or the needs of a family member. We felt dismissed and that our opinions were not considered in any decision-making. WHSTS is important to us because we want to be part of creating change now so that other children and youth will not have to face the many gaps in services that made our lives and the lives of our families unnecessarily difficult.

Some people think that the struggle to obtain accessible supports, services or education has been over for many years. However, many young people with special needs still face barriers and obstacles and we are far from being treated equally and having our rights respected. It was important for the Advocate's Office to collect the stories of young people, their families and supporters through the submissions process because in the fight for human rights and social justice the voices children and youth are often silenced. Our goal was to give young people with special needs an opportunity to work together and use their ideas and lived experiences as a springboard for positive change to supports and services, government policy and public attitudes towards us. Our hope is that this report will show that there is strength to be found in working together with our families and supporters as we build an ever growing community of youth able to advocate for themselves and one another.

Working on the report stirred up a mixture of feelings and was an emotional process. There were too many gaps in services that continue to be faced by children and youth with special needs today. We need change and we need it now. Working on the report was also exciting. We really felt that we could see change starting to happen; to us this report is a symbol of hope.

It is also our hope that once government and service providers read the report they will realize the necessity of actively working in partnership with young people, their families and allies. We feel that many of the gaps in service that exist today are due to the fact that there is a need to establish a process for ongoing collaboration

between ministries, stakeholders and the young people whose needs are met through the services and resources provided by ministries and service agencies. We also want to say that all levels of government should actively review their policies concerning children and youth with special needs and work with our community to make needed change. As a community, young people with special needs must be taken seriously by government and professionals because we are the experts about our own lives and many of us understand what many of our needs are. This knowledge is important and without it policies and programs will continue to fail to meet our needs.

Working on this report has been life changing. We have learned so much from staff at the Advocate's Office, the Youth Advisory Committee and families and supporters who made submissions to the project. We have built many new and sure to be lifelong friendships. We want to say thank you to everyone who has supported the initiative. Your support means a lot to us. Everyone who has contributed to the report project has shown us how we can support and connect with each other. Watch out because there is more to come. From our hearts—thank you!

Handwritten signatures of Salvatore and Holly in black ink.

Salvatore (Sammy) and Holly
YOUTH AMPLIFIERS

LETTER FROM THE ADVISORY COMMITTEE

As members of the Youth Advisory Committee we are excited to have played an important role in helping create this report. We are a group of approximately 30 who responded to an invitation from the Advocate's Office to help bring the voices and experiences of young people with special needs to the attention of government and the service system. Some of us joined the committee when it first started in 2013 while others of us have joined the team over the course of the work. We range in age from 8 to 30 and come from across Ontario; from large cities like Toronto, rural communities, northern towns like Sioux Lookout and remote and fly-in Aboriginal communities in Ontario's north. We bring our lived experience to the advocacy and project work of the initiative. Some of us have special needs ourselves and some of us are siblings of a brother or sister with special needs.

Those of us with special needs have abilities that vary as much as our ages. Some of us are students in public school, high school, college or university. A few of us are struggling to live semi-independently or are seeking employment.

In our own unique and individual ways our lives have been affected by government policy and a service system that has let us, our siblings and our families down. While

we are grateful to service providers, teachers, medical professionals, social workers and other supporters who have helped address and meet our needs and respected our rights, we also live with the impact of the serious gaps between policy and practice and between government promises and the services that are part of our day to day lives. Many of us have spent our lives struggling to have our needs met and to be heard by decision-makers and service providers who believe they know better than us what is in our best interest and what our needs are. As brothers and sisters many of us are frustrated and angry as we watch our siblings struggle to have their needs met by a system that doesn't listen to them or to our families or remember every child has rights that need to met.

Those of us who live in the north are isolated from the resources our peers in urban centres have access to and face additional barriers and struggles to get our needs met. Receiving the resources you need to meet your health, education or other needs shouldn't have to depend on luck or geography. Plain and simple, we all agree, the system has to do a better job for all of us.

We all have our own personal reasons for wanting to become Advisory Committee members and to work on this report, but we all see how important it is for us to work



together to end the ignorance and silences that get in the way of change, get in the way of ensuring we all have the services and resources we need as children, as young people. As you read the report you will hear the stories young people and families brought forward in the submissions they made to the IHSTS project. These are the voices of young people and the families who love them. They are telling their own stories in their own words.

Once you've read the report, we are convinced that you will have a better sense of the challenges we face individually and as a community as well as the support we need so we can become valued members of a society that is inclusive and welcoming. We're also convinced that you will want to work together with us to make positive change. If you are a policy person, we are certain that reading this report will help you understand the impact that your decisions make on our lives. We don't want this to be just another document that you file away and forget about. We're real people with real needs and rights not just users of services and we want you to listen to what young people are saying in this report.

We on the Youth Advisory Committee are proud to have been part of the initiative. We would like to thank

the young people, families and allies who were willing to share deeply personal stories through their submissions. And we want to thank you, the reader, for taking the time to really listen and hear what we are saying. We ask you to read the report with open minds and hearts because what you will learn here is the realities of our lives, told in our own words. We also want you to know that although we are a diverse group of people, we have one common goal: to create a world that is inclusive of everyone.

We want to close our letter by acknowledging our fellow committee member Brandon Gray—"B.G." to family and friends—who passed away while the report was being prepared. The memory of his warm friendly smile, playful sense of humour, friendship and desire to make a difference in the lives of other young people with special needs will stay with us all forever. To his mother Debbie, brother Braedon and his entire family we honour his memory by continuing the work to have young people's voices heard and to make the changes in the system that are so badly needed—just like Brandon did.

Meet the Advisory Committee Members

ALAA ABDULSADA came to Canada from Iraq seven years ago. He lives in London, Ontario with his mother. In his Iraq he found there was no accessibility or supports for people with special needs. Once in Canada, he began to feel “human” as he says. He dreams of working with other young people to make Canada fully accessible and safe for all of its citizens.

ALICIA BOTTLE says that living with a disability hasn’t made her lose hope in herself; it has given her the courage to try harder for what she wants in life. Also, living in the child welfare system gave her another opportunity to succeed in life and become something great and important. She says that her life experiences have given her the chance to be the greatest and loving mother she can be to her beautiful kids.

ALISSA VAN WYNEN is 19 years old. She is from Vermilion Bay in Northwestern Ontario. Her older sister Tiffany was in a tragic car accident which changed her family member's lives forever. She is honoured to be a part of the Advisory Committee because her experiences with her sister opened her eyes to a range of disabilities that are not always visible.

ALY VAILLANCOURT has been a member of the youth advisory for almost two years. She lives in Guelph with her dad, amazing step-mom and little brother. She has lived with Asperger's Syndrome from a young age and has learned to embrace it. She recently graduated from the Human Services Foundation program at Conestoga College.

ALYSSA SMITH is 17 years old and lives in Toronto. She attends classes in grades nine and ten at York Humber High School. She has a mild intellectual and learning disability and some fine and gross muscle restrictions. She lives with her grandmother, Lynn, who had a stroke in April 2013. They love and support one another and help each other navigate life’s challenges and milestones.



ANUJA SHARMA is a former youth in care who believes change starts with the individual. She hopes to inspire and empower children and youth through advocacy on equality while leaving an impact within the community.

BRAEDON GRAY is twelve years old and lives in Sioux Lookout with his mother and sister. Braedon wants other young people with special needs to hear that he knows how it feels to have a disability and not to, “Worry what other people say...you’re special no matter what!”

BRITTANY MEEKIS is from Sandy Lake First Nation in northern Ontario. She would like to see change happen for children with special needs. As she says, “We can be the voices that makes that happen. Let our voices be heard!”

CHLOÉ GODIN-JACQUES is a 23 year-old student living with cerebral palsy. She grew up in Pembroke, Ontario and is starting her second year at King’s University College in London, Ontario. When she graduates, she is planning to complete a Masters degree in Social Work



and work toward her ultimate goal of working in a treatment centre or hospital setting.

CLARA MCINTOSH is in grade eight at Glen Shield public school in Thornhill, Ontario. She is a natural advocate who wrote her first protest letter at the age of 5. When she was 9 she sent a video message to the premier of Ontario. Both Clara and her brother are on the autism spectrum and both sit on the Youth Advisory Committee.

CLIFFORD MCINTOSH is 16 years old and has been with the Advisory Committee since it started and when there were only 5 members. Now, Cliff does the play by play announcing for the Orangeville Ice Crushers in the Greater Metro Hocket League (GMHL). After all the hard times he's been through, he has come so far and is proud of his achievements.

COLE WOODWARD is 9 years old and has an unknown form of muscular dystrophy and other complex medical issues. He is interested in inclusive recreation and has helped local communities put together a sledge hockey

team and a challenger baseball team. Cole may be in a wheelchair but that doesn't stop him from participating just like his able-bodied friends.

ELISABETH CONTINI is 19 years old and currently studying Tourism and Travel at Sheridan College in Oakville, Ontario. She enjoys travel and singing and has been part of the youth advisory committee since June 2015.

ELSBETH DODMAN is a graduate of the University of Toronto with a major in Fine Art History and Anthropology. She recently graduated from the Autism Behavioral Sciences Program at Fanshaw College. She lives in London Ontario with her family and has been giving presentations on autism since she was 18 years old.

EVERETT KITCHKEESICK lives in Dryden, Ontario but grew up in Sioux Lookout. He originates from Lac Seul First Nation. He has been a strong advocate for children & youth since he was very young. He is passionate about standing up for vulnerable youth to help better their lives. He likes to use humor because he feels that, "Life doesn't have to be serious all the time."



FALUM GIBSON will begin studying Criminal Justice and Human Rights at Carleton University in September of 2016. She is an advocate for accessibility issues in Ontario and strives to create a barrier free Canada. She has demonstrated that with hard work, dedication and perseverance you can achieve your goals.

HIBAQ ABDI is a first year student in the Dalhousie University Social Work program. Previously, she completed a Bachelors Degree in Media Information and Techno-Culture at the University of Western Ontario. She became involved with the Youth Advisory Committee after creating her website Froshability, a resource for individuals living with special needs in Ontario.

JILLIAN FERGUSON works in the health care industry as a paediatric physiotherapist. She has been attending the Youth Advisory Committee meetings since hearing about the “I Have Something to Say” campaign on the radio. She feels lucky to have met such an extraordinary group of individuals creating change for children with special needs.

JOSH LAMERS is a social work student at Ryerson University. He grew up in Midland Ontario and volunteers as a youth advocate on behalf and alongside his brothers who have experienced disabling attitudes, policies and

practices due to their different abilities. His goal is to confront ideas about the Disability community and to create accessible spaces for all.

JOY WESLEY is 14 years old and lives in Sioux Lookout, Ontario. Joy loves animals and runs her own after school dog walking business. She is an “A” student in grade 10 and knows the challenges and strengths of living with FASD, being involved with the foster care system and dealing with trauma. She wants other youth to know that they are not alone.

KATRINA MACGIBBON has a Masters degree in Developmental Psychology and Education from The University of Toronto. She recently returned home from Dhaka, Bangladesh where she worked with the United Nations on children’s rights. Presently, she is working with Free the Children in Toronto and has been a supporter and volunteer with IHSTS since 2014.

KELSEY LECOURE is a Finance student at Sheridan College in Mississauga. She is 20 years old and was born with Osteogenesis Imperfecta (brittle bone disease). Kelsey is dedicated to raising awareness of issues that people with special needs face, as well as laws regarding service animals in Ontario.

KRISTINE DOGGETT is 9 years old and younger sister to Joy. Joy lives with special needs. Kristine believes that all people, despite their differences, disabilities or varied abilities should be loved and accepted. She believes that differences and disabilities don't define a person and wants all people to be valued and treated with respect.

MADISON STURMAN thinks her best friend—who has autism—is an amazing, kind and beautiful person inside and out. Madison became involved with I Have Something to Say because she wanted to help give young people with special needs the chance to do whatever they choose without judgment or without feeling they need the approval of others.

NICOLE TURNER is a social work student with a passion for advocacy. She began public speaking when she was 11 years old, promoting ability awareness and the debunking of stereotypes. She hopes to have a career in social policy and advocacy work after attaining her Masters of Social Work degree.

PATRICK MATTHEW has successfully completed his first year of the Community Worker Program at George Brown College and secured a scholarship through the Children's Aid Foundation for his second year. He lives in East York and spends his time at home gardening, listening to the radio, reading and writing science fiction.

RANA NASRAZADANI is in her second year at York University studying Humanities. She was an ambassador for Holland Bloorview Kids Rehabilitation Hospital Foundation for over fifteen years. She has personal experience in advocating for the rights of people with special needs. After her studies, she plans to pursue a career in law with a focus in human rights.

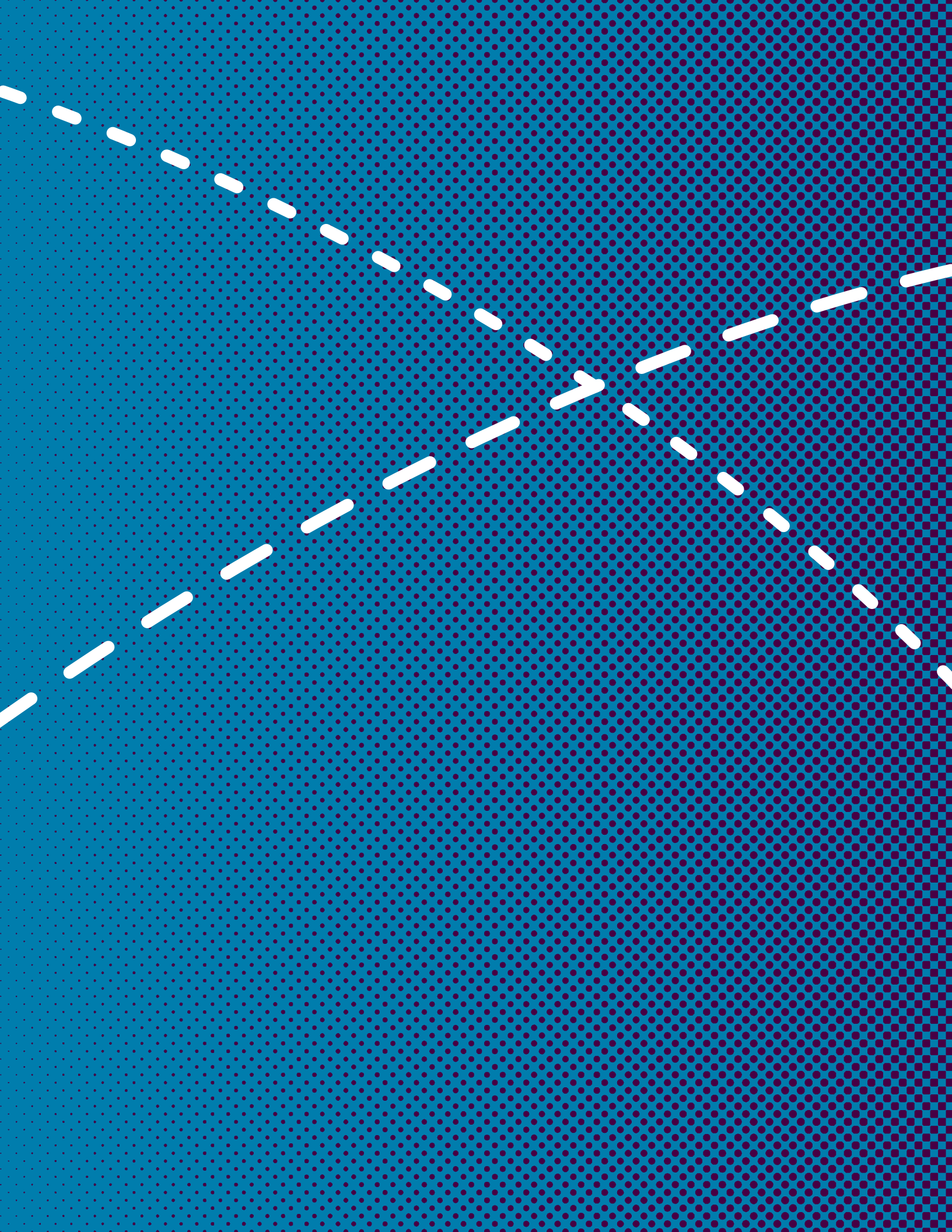
SHAWN FIDDLER is originally from Sandy Lake First Nation. He is proud to be part of IHSTS and share his experiences of how to live a good life and be a role model for other young people who have special needs. Shawn is interested in sharing his experiences with young people from all across Canada.

TARYN BARCLAY is a nursing student who is committed to advocating for and improving the lives of children and youth with special needs in both the community and in healthcare settings. Taryn's experience working with an individual with cerebral palsy led to a lasting friendship and provided the inspiration for her to become an advisory committee member.

TIM ROSE is a longtime disability advocate living and working in Toronto. He has a Masters of Law degree in Human Rights from the University of Nottingham. He is the founder of Disability Positive Consulting. Tim believes that he was lucky to be born with cerebral palsy and that his disability is a powerful part of his identity.

TIFFANY ECKLEY lives with her family in Vermilion Bay in Northwestern Ontario. She acquired a traumatic brain injury in a car accident when she was 17. She was comatose for 9 months and upon regaining consciousness had to re-learn everything. She is an advocate who understands the many obstacles young people with special needs face everyday.

ZAK PRIEST is 23 years old. He lives in Mississauga, Ontario and is studying marketing at Sheridan College. Zak has cerebral palsy and finds great importance in advocating for himself and others. Zak's passions are music and playing video games.





SECTION 1

Family & Home

FAMILY AND HOME

The importance of strong, loving families in the lives of youth with special needs cannot be understated. Parents are committed to helping their children live full, productive and happy lives and need to know they have responsive working partners in government and the service system. Unfortunately, too many young people with special needs and their parents constantly struggle with a complicated service system to find even the most basic supports and services. Their stories reveal that they are frequently stretched to their limits. They encounter long wait lists, rejected applications for needed funding and poorly coordinated assessment and treatment services and resources.

Their experiences dealing with slow-moving and often unhelpful bureaucracies/ government processes make the case for rethinking the decision-making process when it comes to supporting children and youth with special needs. Young people generally know themselves best, but may not always be able to articulate their needs. Families often know their children's needs better than professionals in the service system but those professionals often disregard what parents have to say. Young people want greater ownership and personal control over the decisions that affect their lives and futures. Parents tell us they must have easy access to the information and resources available to meet the needs of their children.

"We wish our families didn't have to work so hard."

Many of the submissions we received for the IHSTS project made a similar point. We heard again and again that families raising children with special needs are struggling with a system that lacks coordination and resources needed to meet the needs of children and keep families strong and healthy. As a result of these systemic challenges, parents are sometimes unable to meet the needs of their children. Some find themselves in an unfortunate situation where they earn too much income to qualify for government funding to meet their child's needs, but don't earn enough to provide proper support without assistance. Other families simply can't find resources at all.

Families providing care to children with special needs are struggling both financially and emotionally. Submissions made to the IHSTS project stated this repeatedly. Families told us they experience real hardship raising children with special needs, because it is difficult to access the resources their child needs to live well in their own homes. Sometimes, the problem is that parents simply don't know where to turn. We heard from young people who said their parents were trying their best, but that they often didn't know where to turn for help. The young people making these submissions wondered why the school system, for example, didn't do more to support their parents and families by providing more education options. They also wanted to see family support personnel be more proactive in advocating for them and more open to listening to their and their family's feedback. They wanted better communication between support workers, service providers and families.

Young people told us they wished that more information and support were available for their siblings, such as having contact with other families, children and young people living with similar situations. This would help build in more support systems and give

We have found our understanding and information to support our son from a small group of parents and professionals. There are no children's mental health agencies offering families any information or support for these children.

Wendy, PARENT

THE GAP BETWEEN NEEDS AND RESOURCES

While there are programs and tax credits available to children with disabilities and their caregivers in Canada, a common thread is that a gap exists between resource needs and resource availability, particularly for low-income families.¹ A main reason that parents of children with special needs do obtain more help caring for their child is that the cost of needed services and resources are too expensive to pay for on their own and are not reimbursable. Also, parents are sometimes forced to quit their jobs or reduce their hours, thereby reducing their family income, in order to care for their child with special needs.²

1. Source: <http://openpolicyontario.com/wp/wp-content/uploads/2015/12/every-ninth-child-report-final.pdf>. pg 16.

2. Source: <http://www.statcan.gc.ca/pub/75-006-x/2013001/article/11858-eng.pdf> pg. 1.



families a chance to exchange tips and ideas about providing their child with care.

The submissions made it clear that families often felt isolated from mainstream society. Many told us that they felt alone in their struggle with the system. Sometimes, they said, they even felt separated from one another within the same home due to the stress of being continually overwhelmed by life's challenges. Many of the people we heard from simply wanted to feel less alone with all their worries.

There was a commonly expressed view among parents that however hard they tried to support their child with special needs, they never felt it was enough. This feeling that they should be doing more has been documented.¹ We as an Office find it troubling when families carry with them a sense of inadequacy about the quality of care they can provide to their children when the source of the problem is a lack of resources and a lack of coordination among support services. It was clear from reading the submissions that families raising children with special needs are frequently forced to make choices other families do not have to make. Far too many parents are forced into making choices to reduce their work hours so they can care for their children with special needs. The very foundation of their ability to meet the needs of their child can be weakened by financial insecurity as paying the bills becomes secondary to caring for their child.

1. Source: <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2008009-eng.htm>.

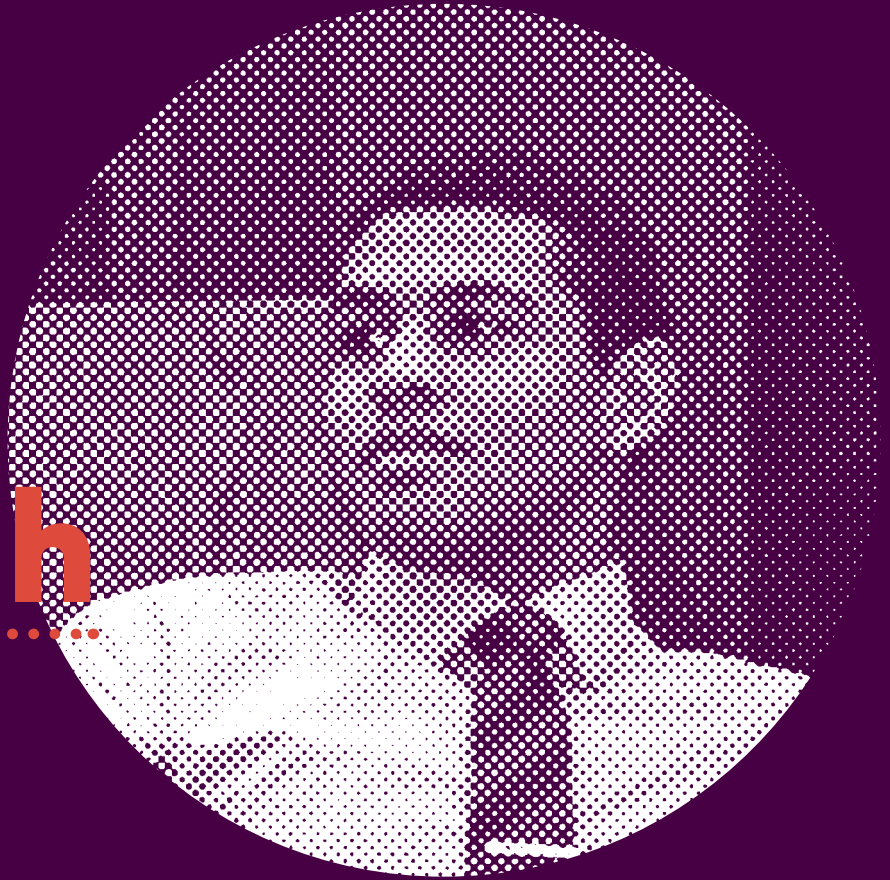
Growing up, I definitely felt like I was the only person with a family situation like mine. I didn't meet any other siblings of children with disabilities. It was all very focused on my brother. I think a lot of time the siblings have to carry on as a normal person, and at home they have a lot of responsibilities, and unique situations that could be very stressful.

Anonymous, YOUTH

I think something that needs to be looked at is just how can families be supported, especially those who have racialized or ethno-cultural families, to make sure they're accessing supports and services.

Anonymous, SERVICE PROVIDER

Josh



"I grew up in Midland Ontario. That's 2 hours north of Toronto. I was adopted, so that's when I moved to Midland when I was 4 years old. Before my adoption I lived in the Orillia area. I spent all my time in Midland, pretty much until I graduated from high school. I have a bunch of siblings. I have one sibling that I'm related to through adoption and his name is Jason. Jason has autism. I was around 8 when I remember things getting really hard. There was a lot of yelling in my home between my parents and Jason sometimes or just between my parents. There was a lot of my parents having to come to the school to pick Jason up for some reason or another or because Jason was being suspended for some reason or another. It was so chaotic in the house.

My brother was getting suspended all the time for behaviours that were basically related to autism. That was pretty consistent throughout my childhood and adolescent years being a teenager. It got to the point where being in school pushed Jason to being suicidal. My mom was like "I'm going to home school him. This is getting ridiculous." There was stress on everyone. The biggest thing when I was young...I would cry. I cried when they took him away [to a children's treatment centre]. I still remember that to this day. But then, when he wasn't home, my parents were able to put more attention on me."



The Stress on Parents of Providing Care

The severity of their child's health has a direct impact on parental stress. The more severe their child's disability, the more stress parent's report experiencing.¹

1. <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2008009-eng.htm#2>.

In my case, my family didn't understand my learning special need. My parents didn't know how to support me. They didn't know where to go. There's many ways to support your child but they didn't have the deeper understanding.

Sammy, YOUTH AMPLIFIER

Winter is a huge challenge, I'm sure, for many families just in accessing services and programs. It is so hard to figure out what to do in the winter, and there's only so many times you can go to the science centre and actually enjoy it, or the museum.

Anonymous, PARENT

As a sibling, it not only affects the individual with a special need, but also someone who is growing up with the person at the same time.

Holly, YOUTH AMPLIFIER

Some youth prefer to talk to other adults rather than their own parents. They don't want to let their parents know what they feel and don't want to be judged and have what they say used against them and feel ashamed.

Alicia, YOUTH ADVISOR



We also heard from professionals about the physical and cultural barriers that families face in accessing the resources that could lessen the care-providing challenges of everyday life. In particular, we heard that some families do not seek supports out of feelings of shame or embarrassment tied to cultural beliefs and views about seeking help or about the social or spiritual meaning of having special needs within their culture. Professionals who made submissions want government to put resources into exploring educational opportunities for newcomer families, and their community organizations, so they have a better understanding of their child's experience, the service system and special needs in general.

Families told us stories about the challenge of caring for their child during the winter months when mobility becomes a real issue because of a medically fragile child's sensitivity to cold temperatures or the accumulation of ice and snow on public and private property that blocks the way for young people in wheelchairs. Families are also calling for more public awareness of the needs of children and youth with special needs so that sidewalks are kept clear of snow, ice, tree or shrub branches or garden debris.

"It's stressful for us when we have to leave home."

Families raising children with special needs often carry a heavy workload that may include the need to provide one-on-one educational support, around the clock medical care, transportation to medical and other support service appointments, support during hospitalizations and much more. With all this additional work, parents can end up focusing a great deal of energy on their child with special needs and any siblings in the home can feel forgotten and choose to not add their own needs to the stress their parents/caregiver are already managing. Many families in this situation suffer from constant high levels of stress.

Respite care is essential

We also learned from the submissions that there is a flip side to providing constant care at home. Some families with children who have special needs said they experienced severe burn out from the challenges of raising their child. Families told us that they need more respite care and that receiving it can mean the difference between a child with special needs living in the home or being placed for extended periods in care outside the home. In other words, respite care can mean the difference between a child and family simply surviving day to day and truly thriving.

One family told us of having to place their child in care of a centre or longer term resource for months at a time so they could regain

As hard as it has been being a mother of the children I have, that job has been made so very much harder by the government's systems. From the first day you reach out for help with your child, it's like a highly judgmental never-sleeping set of eyes enter your life.

Anonymous, PARENT

Home is where you want to be. The people I love are there. I don't want to move. My home is part of my heart. I feel safe in my home when I'm around my mom, sister, my gate and my trees.

*Braedon, YOUTH ADVISOR AND
BROTHER TO BRANDON*



Families supporting a son or daughter with special needs live in constant tension, worried that their child will not get into the right school placement, recreation program, or social group, all the while struggling to obtain appropriate financial support and nursing or personal support worker support.

Dawn, PARENT/CAREGIVER/GUARDIAN

the strength to provide high quality care. Another said that if government had given their family access to more care options earlier, their daughter would still be living at home.

Families should never have to face the prospect of giving up a child with special needs to the care of the state/child welfare because of an overwhelming lack of support. If more options for respite care, day treatment programs and supports in home were available, more children and youth with special needs would be able to live at home permanently with those who understand their needs, make them feel safe and love them most.



Falum

"I wish my mom had more support. Not as in more people, because she had a lot of people around that were willing to help. But, if she had more resources, and more money, she would be able to get equipment. That's really what her struggle was. She would literally have to do all the lifting herself. It was just really hard for her, because I was getting bigger. So it would put a lot of stress on her back. Then she would feel like she was letting me down, because sometimes she really just couldn't do it physically. With special equipment I could become more independent, and she wouldn't have to be around 24/7. Because when you're

older you start wanting to go out with your friends.

At that point none of that was happening for me, so it was kind of hard for her. Then it got to a breaking point where she said, 'I can't do this anymore.' It was never an issue if they could support me emotionally. 100% they were there. They would do anything for me. But, it was more of the physical stuff. When I look back, I wish my mom sort of had spoken up more, and asked for more funds to help her. But even when she did speak up she got discouraged, because there wasn't anyone listening."

If my son could express his thoughts I am sure he would say, 'Please give me access to a computer or TV so I can watch all the movies I want, especially Disney, and give me tickles and a steady daily routine. Please do not send me into a psychiatric hospital for seven months again because my caregivers are burned out and there is nowhere else to get help for them or myself.'

Doriane, PARENT

This is the issue: the families who care about children with special needs and are supporting them aren't allowed to talk or make any suggestions to the school board or community housing.

Josh, SIBLING AND YOUTH ADVISOR



"We need professionals to see us — parents and young people — as experts on our own lives."

We were told that government and service providers need to acknowledge that families know their situation better than anyone else and that their knowledge should be used more in decision-making about all care that is required. This knowledge should be recognized for what it is: expertise about their lives.

Families raising children with special needs often work with a range of professionals—from teachers and coaches to therapists and doctors. Parents and young people told us that they wished the professionals in their lives would respect their knowledge about their situation, stick up for them more often and listen better. Many expressed a vision for a system in which the professionals who work with them have advocacy built into their roles.



Instead, the reality presented in their stories is one of frustration in having to deal with a complicated network of professionals, particularly in the medical system. In some submissions, parents spoke about the stress of dealing with insensitive medical professionals and of having no recourse or complaint mechanism when they or their child received poor treatment.

Families told us that they want doctors to acknowledge and build on the abilities that their children possess rather than focus solely on their special need. They want a service system in which their children are accepted as individuals, with unique strengths and preferences, and in which their children are viewed as being more than simply a “diagnosis”. In short, young people and their families want to work with service providers to create a system that does not judge and that recognizes and appreciates the unique knowledge and skills that families possess to provide for their children with special needs.

Young people and their families also recognized that many medical and other service professionals were highly respectful of young people and their parents and provided compassionate skillful care. But, as we heard in the submissions, even when the behavior of individual professionals was admirable, the system itself repeatedly failed to provide families with the resources they needed to help their children thrive at home. We heard stories of families suffering lasting mental health issues following lengthy and traumatic stays in hospital with their children.

When I reflect on that journey I have come to realize that had the government listened and offered readily available alternatives to living at home group homes Chelsey would have stayed at home with her family longer.

Deb, PARENT

Putting ourselves in his place makes it easier for us to discover and develop his potential and allows us to help him find his own voice. We always try to understand how his mind works by watching his nonverbal reactions. We are also very mindful of asking his permission before we intrude on his personal space, and by doing so help him to maintain his dignity despite his intensive caregiving needs.

Myles, PARENT



Andrew

"Andrew was born premature and has Cerebral Palsy. He is non-verbal so a lot of the communication is kind of heart-to-heart communication. We have a form of communication that is very silent, but very connected and very strong. We know when he needs help. My parents and I know him best. The negative part is the limited communication that he can have with other people. He can only communicate with his tongue, and he can only communicate to express what he feels based on other people's questions. He can't initiate any conversation about his needs. Only if people ask him, 'Do you need water?' can he say 'yes', or 'no'. This is the difficult part. It has to be someone initiating a question. And it's a yes or no question that he can respond to. So that's why I feel he feels very insecure when my parents and I are not there.

At school he has a caregiver. She is a long-term caregiver. So we are ok with him going to school with her. But if it's a summer camp where it is 1 or 2 weeks, or a few hours a day, it's his being around new people that worry us. Other children, if they can't communicate, maybe they can move their arms or something. But my brother is completely unable to move and unable to communicate, so maybe vulnerable is another way of describing the way he feels when he's not with his family, or in a unique environment; a different environment. Every environment we put him in is an environment that wants to help him, or improve the quality of his life. We won't put him in an environment that doesn't do that. At the same time, he definitely feels vulnerable."

—Holly, SISTER TO ANDREW

We brought the NICU home with us in the form of monitors and oxygen. Unfortunately, the most important component, the human connection; vis-à-vis the staff—was absent.

Christine, PARENT

I have always tried to give my son the most normal life possible and one of the biggest challenges has been that the system puts the wheelchair or union policies ahead of the person.

Mother of Jake

You are afraid to ask for a second opinion. You get the doctor who says this is the answer and that's it.

Anonymous, PARENT

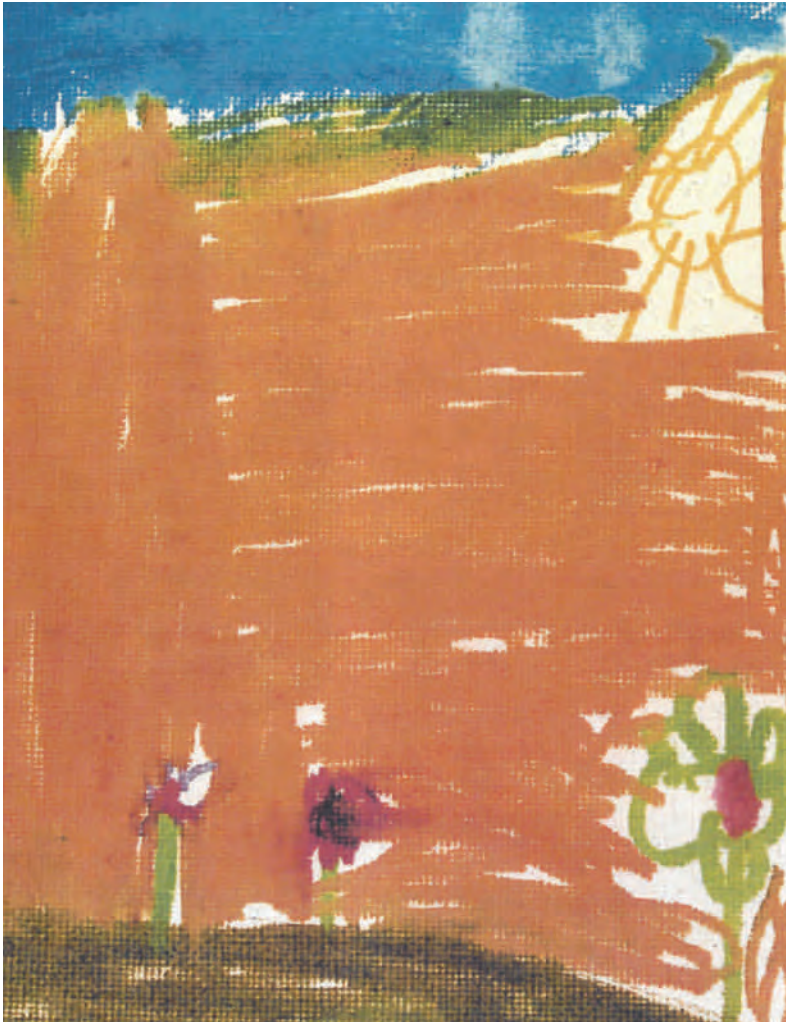
"We need our dignity and our personal space."

In some submissions to the project, parents spoke about situations where people treated their children without common courtesy or respect. Young people stressed that the discrimination and stigma they often faced presented barriers to living full and happy lives. They expressed frustration that some people in society cannot understand that young people confined to wheelchairs have the same feelings as other children and youth. Hurtful words and hurtful actions affect young people with special needs deeply, regardless of the nature of their special need. This leads to feelings of exclusion and isolation.

Worse, many people with special needs who cannot communicate can understand others perfectly. It is hard to imagine how it feels to be treated as though you cannot hear or understand when you can do so perfectly well. Young people with special needs just want supportive environments in which they are enabled to "do things" as one youth said.

An overarching message in the submissions is that children and youth with special needs want to feel included. They also want the people in their lives to challenge them and expect a lot from them, as low expectations tend to result in underachievement. We heard again and again that just because a young person has a special need, it doesn't mean they can't achieve and excel.





"Our families love us very much."

Deep love and affection was evident in the submissions, as siblings and families expressed their devotion to their loved ones and their determination to do right by them. Families are committed to help all their children live the joyful, productive and satisfying lives they deserve.

Many families told us that they celebrate and honour simple day-to-day accomplishments of their children: swimming enjoyed by a child who cannot walk; a simple smile from a child who cannot talk; gratitude that although a child cannot talk, walk or move, they can smile and laugh. We heard from young people with special needs who felt understandable frustration that they could not participate in sports

I think it would be helpful if somehow my mom could get compensation for all the work she does.

Nicole, YOUTH ADVISOR

Families navigate a medical system with great difficulty and great frustration before they even begin to navigate the educational system, and they deal with people who are patronizing to them and people who are insensitive to them.

Anonymous, PARENT

We need to change how people view us. I'm tired of people thinking that we're basically babies and we need to be spoon fed. I just want people like me to be treated normal, as if I don't have a special need at all.

Anonymous, YOUTH

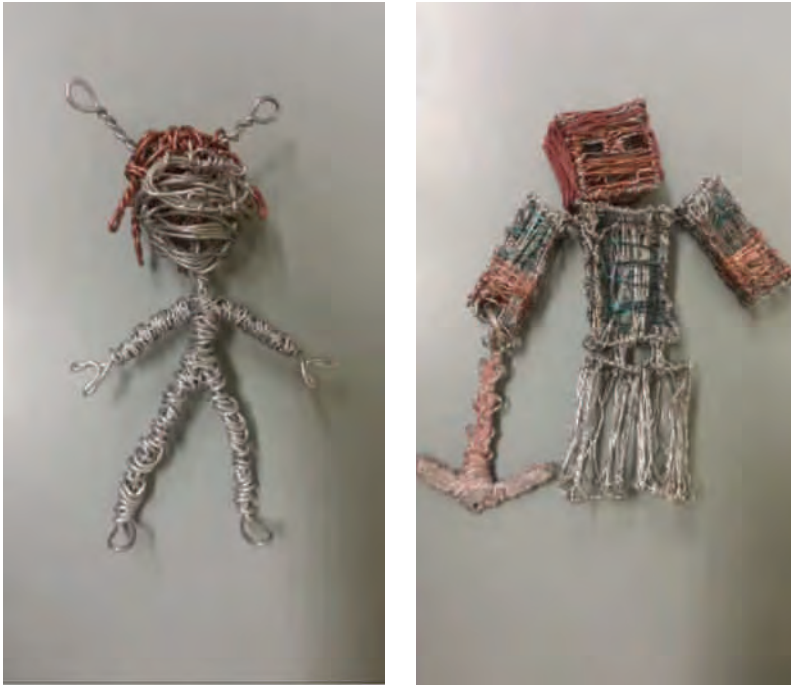


Everett

"I have FASD, or Fetal Alcohol Spectrum Disorder. At a young age it affected everything. It affected me in every possible aspect. I was getting into scraps with other kids in my class, like everywhere. I ran away from home. I got told in the majority of my school classes I am going to be a great failure that I'm going to be someone who cannot achieve anything. I was just a violent little kid. I couldn't control my anger. Then I was taken from my mom and put into care. I moved around to a lot of different foster homes. The foster parents and I were always in constant battles. I was always arguing with them, fighting back with them. I got to be in a

really dark place. I didn't know where I was going to live or what I was going to do.

Then one day [the CAS worker] said 'don't worry about it, Rhonda is going to take you in as her own child'. I was so happy. It was just heartwarming. Then the thought of suicide, that depression, it just left. I lived with Rhonda for 12 long years. She was my mother. Not my biological mom, but my mother. Of course we had a couple of kinks to work out. It wasn't easy at first; I still had a lot of anger to work through but Rhonda gave me advice when I needed it. She gave me everything when I needed it."



or go camping like other children their age, but who nevertheless felt grateful for having a loving family. We also heard from families who preferred to support their children with special needs on their own rather than rely on strangers, community services or government.

Opinions in the submissions were diverse, but we were left with a sense that families raising children with special needs—regardless of their daily challenges and their disappointment with an under-resourced support system—tend to stay positive, mainly because of the love they feel for their children and the love that these young people feel for their families.

Some young people we heard from were not living with their birth families, yet they told us they felt unconditional love for the first time by being taken into a caring foster home and spoke of how feelings of suicide lifted from having finally achieved a sense of belonging. We received a submission about one little boy with cerebral palsy, autism and multiple health problems who weighed 26 pounds at age nine when a professional first encountered him. The boy was placed in a loving foster home and, within 18 months, weighed 69 pounds, had learned to communicate through sign language and tablet de-

People with Down Syndrome have the ability to do a lot of things when we are given the chance to try. People with Down Syndrome can read, write and do arithmetic. We can work and live independently. We can drive cars and go to college too.

Anonymous, YOUTH



vices and had become healthy enough to attend camp with his peers. All he needed was consistent human contact and a nurturing environment to thrive.

Loving care and close connection appeared to be a key component to living well and living happily. In their submissions, parents asked government to provide them with the supports necessary to keep their children at home and free from undue stress and isolation.

While my daughters have a physical special need, they are always happy, positive and full of life. Gisele loves art and Sienna, while she can't walk, can swim independently like a fish. My wife and I are very positive people. We focus on their abilities not special needs.

Noor, PARENT

My mom was a very strong and independent woman. She wasn't going to let anyone tell her how to raise me. So, from the beginning she raised me the same way as my brother. That helped a lot. I used to crawl around on the floor. My brother used to wrestle with me. I was just like any other kid.

Nicole, YOUTH ADVISOR



Initially, we didn't know how to get support. That really isolated my family for a while. Also, I wanted to make sure that Krystal would forever be supported by us. We were not too keen on outside support. We were a family and we shared the work. One daughter would be in charge of taking her to the washroom, changing clothes, taking her to the bath. Our second daughter was in charge of medication and cleaning up the toys. It was a little tough on their mom because she had a full-time job too.

Father of Krystal



Shawn

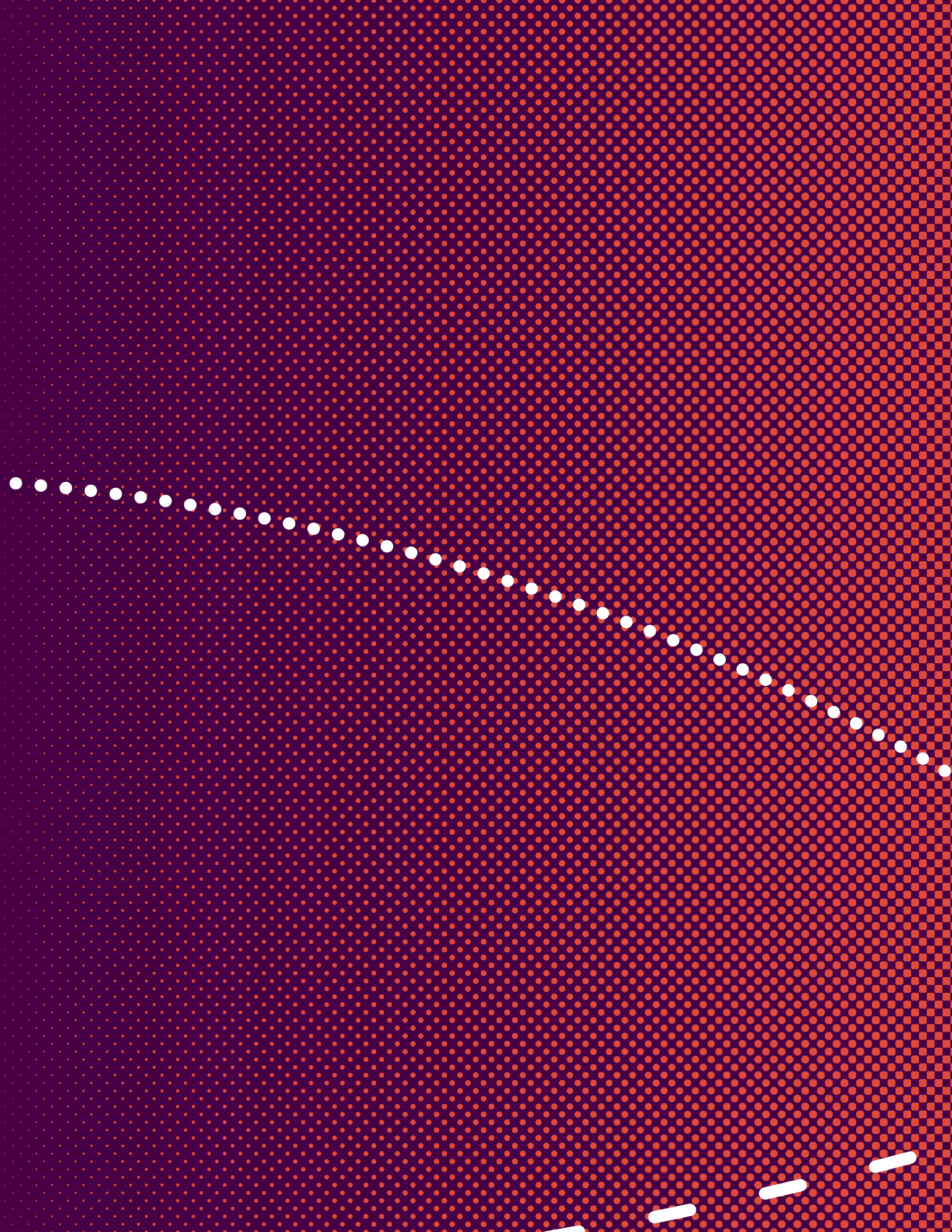
"Love is the most important thing you can have to support you. I never got any care or loving from parents when I was younger. Good parents are another thing that young people with special needs need. I had one set of foster parents who gave me everything, they spoiled me and my little brother, but they moved away and now I don't know where they are. I have some pictures of them in my room. I always think about them because they were like my mom and dad. I probably lived in like 20 different foster homes. I always got into fights with my foster siblings. I was homeless for a few months and breaking into garages just to keep myself warm. Then I moved in with Rhonda and that helped me get supports. The supports I have in my life make a big difference. People like community living and Rhonda, Bill and Debbie, my other foster parents, they are really good people. If I had had these people in my life when I was younger it would have been easier.

When I was younger I didn't even know I had a special need. I knew that there was something wrong with me but I didn't really know what it was. Now I understand that everybody has different strengths and weaknesses whether you have a special need or not. When it comes down to it we are all the same because we are all human beings. Now I follow the 7 grandfather teachings, love, truth, wisdom, respect, honesty, bravery, and humility. It is important for me to stay connected to my Aboriginal culture by smudging and being at the drum and being a grass dancer. I've been dancing for eight years. I'm 23 years old now and I didn't have the regalia until now. One of my friends gave me my regalia; it is a Thunderbird with flowers on it. These things heal me. They help me to deal with my baggage."

RECOMMENDATIONS

FAMILY AND HOME

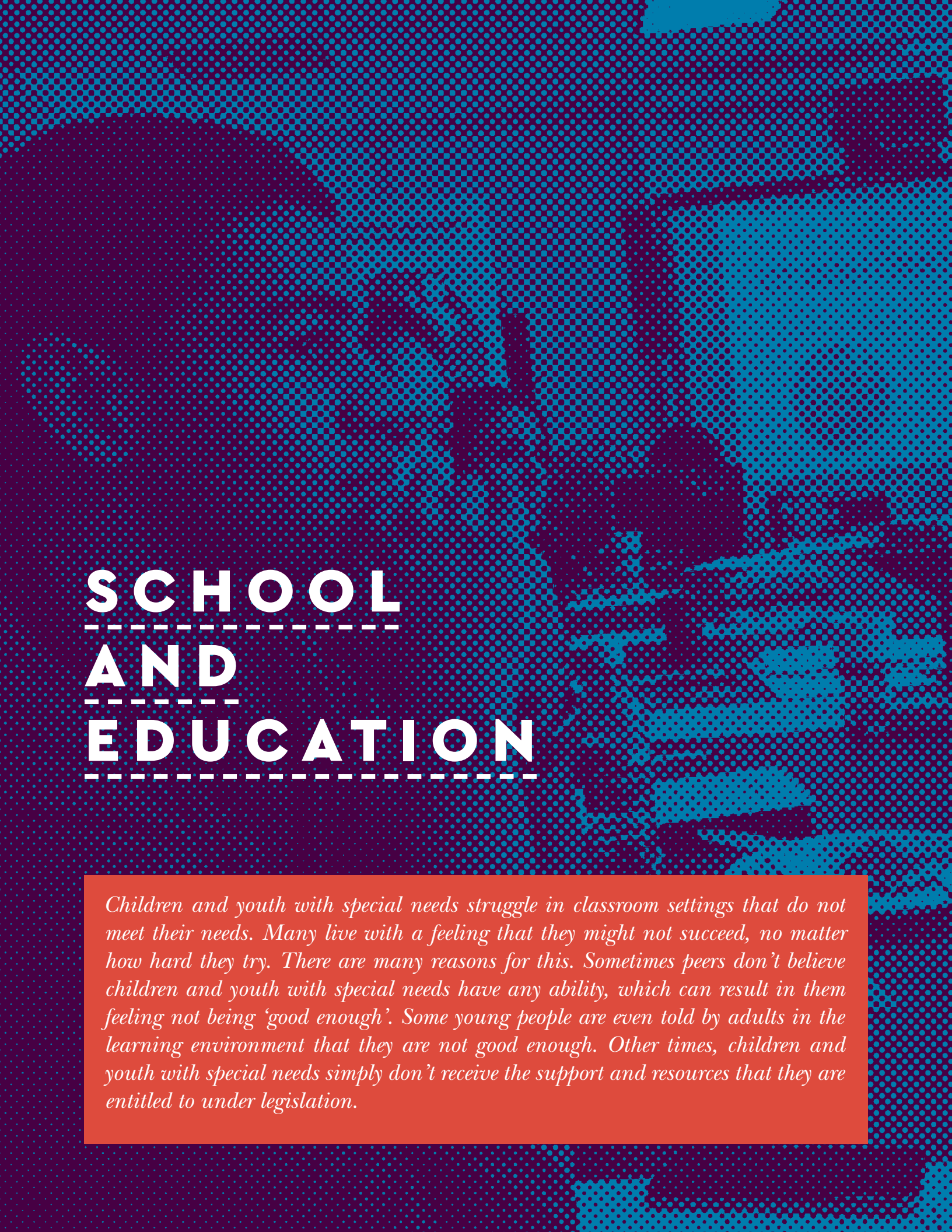
- 1.** All levels of government and service providers in Ontario must recognize and respect the knowledge that family members have about their children. Most of all, decision makers must recognize and respect that children and youth generally know themselves best and are the experts about their own life experiences.
- 2.** The government of Ontario must establish an inter-ministerial youth advisory table to address service needs, accessibility challenges and potential of children and youth with special needs in Ontario.
- 3.** The government of Ontario must work with young people with special needs to create a blue print document that will map out next steps in the process of implementing the recommendations in this and all other chapters of this report.
- 4.** The government of Ontario must simplify the application and intake process that children and youth with special needs and their families need to follow to obtain respite, direct funding, and other required services in Ontario.
- 5.** The government of Ontario must establish mechanisms to ensure that all community-based sports, arts, camping and recreational programs and activities in Ontario are inclusive, accommodating and accessible to children and youth with special needs.
- 6.** The government of Ontario must provide all possible in-home supports to families of children with special needs—personal support workers, nurses, nursing support, in-home medical care, developmental services and caregiving support—in order to ensure that children can stay in the family home for as long as possible.
- 7.** Provincial and municipal governments must support, expand and raise the profile of sibling and family peer support programs in Ontario.
- 8.** In-home and out-of-home respite care must be promoted widely to all eligible families in Ontario and made more easily available to families that require it.
- 9.** The government of Ontario must work with young people through the youth advisory table to create more flexible service models for how young people and their families receive supports in their homes, including the use of self-directed funding.



SECTION 2

School & Education





SCHOOL AND EDUCATION

Children and youth with special needs struggle in classroom settings that do not meet their needs. Many live with a feeling that they might not succeed, no matter how hard they try. There are many reasons for this. Sometimes peers don't believe children and youth with special needs have any ability, which can result in them feeling not being 'good enough'. Some young people are even told by adults in the learning environment that they are not good enough. Other times, children and youth with special needs simply don't receive the support and resources that they are entitled to under legislation.

We as an Office find it unacceptable that any adult professional, in any setting, would ever assume that young people with special needs are less able than their peers. We believe that when a student with special needs does not achieve academic goals set by the school, it is not a failure of the individual, but rather a failure of the learning environment to adapt to the way the young person learns.

Teachers are essential co-advocates for their students with special needs and can be a source of tremendous support when they are given the resources they and the young people in their care require. Cut backs in education spending that lead to large class sizes of up to 30-35 students, the loss of classroom educational assistants (EAs) and few opportunities to receive the training they need to support their students with special needs make this particularly challenging. Even the most dedicated and skillful teacher cannot help all students in a classroom when the ‘whole school’ environment is not designed and equipped to be welcoming and supportive of the unique needs of all learners.

“What you believe, we achieve.”

Young people who provided submissions to IHSTS agreed on many things and one of them is that their teachers and the school system often have low expectations for them. These students felt that they have been limited by an education system that has diminished their life opportunities.

According to young people who shared their ideas with us, placing high expectations on youth with special needs is more likely to lead to higher achievements. But, in their experience, the education system doesn’t consistently demonstrate that young people with special needs have the same potential as their peers. Low expectations can affect these young people in many ways throughout their entire lives. It was evident in the submissions that some young people choose not to pursue post-secondary education because they were told they didn’t have “what it takes”. Others were discouraged from pursuing educational opportunities because the schools they wanted to attend couldn’t or wouldn’t accommodate their physical or learning needs. Some were streamed into vocational programming at a young age because of low expectations of their potential to succeed academically. At other times, young people felt that while teachers didn’t actively “discourage” them they failed to “encourage” them, which they felt was just as limiting.

The Education Amendment Act, 1980

On December 12, 1980, the *Education Amendment Act*, also known as Bill 82, was signed into law in Ontario. Bill 82 requires school boards to provide special education services to all students in their schools who are in need. Prior to the passing of Bill 82, most school boards were already providing special education supports to students. With the passing of Bill 82, providing access to education for all students, regardless of disability, became mandatory.¹ This significant change in government education policy entrenched the right to an equal education for children and youth with special needs in accordance with their need and ability. It also brought with it a change in thinking about the learning environment, questions about teacher training and how educators should be resourced and supported to ensure the success of all students in the classroom. The shift from segregated learning environments to inclusive classrooms for all learners has its strengths and its challenges many of which are raised by young people with special needs and parents who made submissions to IHSTS.

1. Source: www.edu.gov.on.ca/eng/literacynumeracy/inspire/research/Bennett.pdf

Why do people fail to have high expectations of children and youth with special needs? The Advocate's Office is convinced that students with special needs can be and are some of the most capable young people in the classroom. They often look at the world in different and creative ways, ways that reveal strength and imagination, challenge the limitations of current teaching and alter dated ways of thinking about how students learn.

"To succeed we need the right supports."

What is clear from reading young people's submissions is that children and youth with special needs can and do succeed in academic programs—provided they have the proper supports. Unfortunately, the provision of needed supports is often delayed, can be provided in ways that are inappropriate for the young person's needs or can sometimes fail because teachers, educational assistants and other support staff lack the training to provide them correctly.

Research submitted to IHSTS by allies of children and youth with special needs reveals that progress is taking place in at least recognizing the importance of providing individualized support for children with special needs. But it also reinforces the difficulties inherent in providing individualized support and that there is still much work to be done in Ontario in this area. The research says that the practice of putting children and youth with special needs in mainstream schools has inspired a shift toward individualized teaching approaches that recognize each child's complex needs.¹ That is positive news. On the

Children and youth with special needs would like it if teachers would not "dumb down" classroom work for us, but instead adapt their teaching methods to our specific abilities and how we learn. We need teachers, not babysitters—teachers who will to listen to our dreams and aspirations and help us find ways to realize them. Otherwise our school lives are about limits rather than achievement.

Anonymous, YOUTH

1. Source: McLaughlin et al (2006). Cross-cultural Perspectives on the classification of children with disabilities: Part II, implementing classification systems in schools. *The Journal of Special Education*. 40(1): pp. 46-58; Florian et al (2006). Cross-cultural perspectives on the classification of children with disabilities: Part I. Issues in the classification of children with disabilities. *The Journal of Special Education*. 40(1), pp. 36-45.



Gaps in Supports and Services in Special Education

22% of elementary and **19%** of secondary schools report that not all identified students are receiving recommended supports.¹

57% of elementary **53%** of secondary school principals report there are restrictions on wait lists for special education assessments.²

The vast majority of school boards report that they spend significantly more on special education than they receive from the Ministry of Education.³

Only 39% of elementary schools and **32%** of secondary schools have access to a regularly scheduled psychologist. Scheduled psychologists work an average of 11 hours per month in elementary schools and 16 hours per month in secondary schools. In some schools, psychologists work on-call, but **12%** of both elementary and secondary schools report having no access to a psychologist at all.⁴

1. Source: <https://www.peopleforeducation.ca/wp-content/uploads/2015/06/P4E-Annual-Report-2015.pdf> pg. 16.

2. Source: <https://www.peopleforeducation.ca/wp-content/uploads/2015/06/P4E-Annual-Report-2015.pdf> pg. 16.

3. Source: Gallagher-Mackay, K., and Kidder, A. (2014) Special Education. Toronto, ON. People for Education. Link: <http://www.peopleforeducation.ca/wp-content/uploads/2014/04/special-education-2014-WEB.pdf> pg. 19.

4. Source: <http://www.peopleforeducation.ca/wp-content/uploads/2014/04/special-education-2014-WEB.pdf> pg 10.

I got told in the majority of my school classes that I am going to be a great failure. I'm going to be someone who cannot achieve anything. Everyone called me the school failure because I didn't get homework done. Everyone was constantly calling me down.

Everett, YOUTH

The demand is so huge and the services so few that wait lists of over one year exist for all mental health organizations and services. The programs that exist are usually only short-term with no follow-up services provided. Families are advised to seek help privately. We need a concerted effort from all members of society, all levels of government and all members of the educational and healthcare systems to work together.

Sheryl, PARENT

Today we just found out that I am losing educational assistant (EA) hours in a class because they don't have the people to cover. I'm supposed to be independent, which is understandable, but I'm getting a credit, right? The EA is there to take notes and help me with my work, because when my teacher's talking I can't be typing. I have to listen. And, it's not just notes, but the teacher adds things. So if you're not getting the notes, you're not getting the whole picture. What they promised last year was that we could get as much work done at school as possible. How is that going to work if I don't have an educational assistant?

Amina, YOUTH

other hand, some researchers say that children's special needs can't easily be classified.²

Another study, the national Participation and Activity Limitation Survey (PALS), investigated the experiences of children in the education system, as well as the perspectives of their parents. It found that parents in Ontario were the most likely in Canada to report difficulties in accessing special education services.³ Most often, parents reported insufficient levels of staffing or services as the reason their children's education needs were not being met. Other reasons included not being able to get an assessment and a lack of local support services.

We understand from this research not only that the process of supporting children and youth with special needs is complicated, but also that Ontario is lagging behind other provinces in making progress. Children and youth with special needs and their families who made submissions to the project identified a number of critical areas for improvement which are described in more detail below.

"We need timely diagnostic support."

Many young people reported spending years in classrooms feeling like they didn't have what it took to be successful in school, some even reported being yelled at by teachers and educational assistants and being bullied by other youth. They wanted their teachers to protect them from harm and make them feel safe in class. They also wanted proper assessments and diagnoses of their strengths and weaknesses so that they could get the right support and start succeeding every day.

As a first step, before schools can hope to address this group's needs, each young person requires an Individual Education Plan (IEP). Families told us they also wanted their children to have more readily available access to the Identification Placement and Review Committee (IPRC) process that helps decide whether a student is exceptional and, if they are, what type of educational placement is appropriate for them. But a lack of resources can mean that an IPRC review can take months or even years to happen. Families reported paying up to \$3,000 out of their own pockets for independent psychological as-

2. Source: <https://canchild.ca/system/tenon/assets/attachments/000/000/717/original/fcs2part1.pdf>

3. <http://www.statcan.gc.ca/pub/81-004-x/2007001/9631-eng.htm>



The school also excluded Jason from activities. During the lunch period, they wouldn't let him go outside for recess. Instead, they would keep him inside and send him to the Kindergarten class where his supervision was. They said they don't have supervision for Jason outside. So he has to stay inside.

Frances, MOTHER

assessments because they couldn't stand watching their children struggle while they waited for a diagnosis through the school. It's unfair and inequitable because not all families can afford to do this or have access to professionals who can conduct these assessments, especially in northern, remote and fly-in Aboriginal communities. It is even more upsetting to young people and their families when they know that they are entitled to this resource and that the education system is supposed to take care of the costs on their behalf.

Even once a child with special needs has a diagnosis and an IEP, we were informed that some teachers may fail to follow through on its recommendations. For whatever reason—sometimes it was a lack of resources or a lack of training and support—teachers were unable to make the accommodations outlined in the IEP and the young person's needs went unmet. These young people told us they wondered how these issues would ever be addressed if school staff and government did not listen to either them or their families' concerns.

The situation seemed even worse for young people who were crown wards or in the temporary care of children's aid societies. Some foster parents told us they did not feel they had the skills to han-

Everyone has a different normal. I used to think I was dumb and stupid but now I don't think that any more.

Anonymous, STUDENT



dle children and youth with special needs or to advocate with or for them in the school system. Strict and unbending rules in many care settings were the opposite of what these young people needed to thrive. We heard that because of the perceived lack of support from their caregivers, foster care environments can increase the frustrations of children struggling with unmet special needs who are at the same time confused, angry and fearful about their overall life situation.

"We need classroom support."

It was evident by reading through the submissions that there is a need for more supports in the classroom for young people with mental health needs, needs that often present with physical, social and behavioural differences as well. One major problem pointed out is that many schools face a lack of resources to help their students obtain an accurate diagnosis and support resources.

It was clear in the submissions that motor skills can be a challenge for some students with special needs, and that the solution used to support their learning relies on technology such as computers, tablets

More special education teachers needed in Ontario

37 to 1

In Ontario elementary schools in 2014, there was an average of 37 students with special education needs per special education teacher. While this number has remained relatively stable for the last four years, it is a substantial increase from ratios pre-2010. The ratios range across the province, from a low of 26 to 1 in the Greater Toronto Area, to a high of 52 to 1 in Eastern Ontario. In secondary schools, the average ratio is 74 students for every one teacher.¹

1. Source: <http://www.peopleforeducation.ca/wp-content/uploads/2014/04/special-education-2014-WEB.pdf> pg 2.

My son needs to be able to get through a day of learning without trauma. I need to get through a day of work without being terrified of getting a phone call from the school. While these young people with special needs are in school, budget constraints seem to be a major concern in cutting the levels of daily support available for these students.

Rebecca, PARENT



Jonathan

Jonathan is 14 years old and has a diagnosis of epidermolysis bullosa (EB). We have lived in a continuous struggle since he was born because of the extensive care necessary and the lack of knowledge about EB. EB is not a disease that gets better with time. Even getting into the teenage years, the hormonal change doesn't help. He has a harder time walking. The damage to the skin, unfortunately, is not a pain that heals. Some wounds will heal, some are chronic and will never heal. So, life is not easy. School is tough. He's had a good report card, however, even though he missed 22 days of school this semester. Jonathan's very smart. But, because of the limitations he's got—he can't follow what other people are doing physically—they put him in a class where people have cognitive/developmental disabilities – which he doesn't. He also doesn't have friends his own age.

Since January he has had quite a hard time. It's that these kids with special needs are really, really smart. But they can't keep up with the rest of the class. So, Jonathan has to have an educational assistant (EA) with him every day just to be able to get to school and get around in school without being knocked over by the kids running in the hallways. So that somebody can open his doors. So he can learn what is being taught, things that he can't do himself. He's got to have an EA with him. These services are very important.

—Tina, MOTHER OF JONATHAN

Children with Down Syndrome need to learn to count, read and write just as much as other kids. They need positive role models and should be encouraged to be a part of their peers – not just play games and learn to do laundry, cook and clean, and be separated from everyday people who make and shape the future.

Anonymous, PARENT



and touch screens that don't require a high level of motor skill. The problem with technology is that it's constantly changing and in need of updating. It's also expensive and unavailable or unaffordable for schools, especially those in remote, northern and Aboriginal communities. Government and school boards need to make long-term financial commitments to students who require this equipment so they can keep up with technological changes.

Children on the autism spectrum, with FASD or who have different language ability, as well as mental health needs pertaining to anxiety and depression, can be very vulnerable in school. They face particular challenges over the course of a regular school day when transitions take place—from one classroom to the next, from one teacher to the next and even from one activity to the next.⁴

When children with autism are not provided with the supports they need during school day transitions, they can sometimes act out. Par-

4. Source: http://www.gov.pe.ca/photos/original/ed_autisminc.pdf.

Ontario does not have a fetal alcohol spectrum disorder (FASD) strategy within its Ministry of Education, and school boards are thus ill-equipped to identify, manage and assist students with FASD diagnoses and/or presenting symptoms within their schools.

Katie, PARENT

The Need for More Opportunities for Post-Secondary Education

Only **59%** of students with a disability attend post-secondary education, while **72%** of non-disabled students attend post-secondary education.

Only **49%** of students with a severe disability attain a postsecondary education, compared with **56%** of students with mild disabilities who attain the same.¹

1. Source: Higher Education Quality Council of Ontario, Government of Ontario. Disability in Ontario: Postsecondary education participation rates, student experience and labour market outcomes. Ontario. 2013. Available online at http://www.heqco.ca/SiteCollectionDocuments/At%20Issue%20-%20Disability%20in%20ON_ENG.pdf pgs. 7-8.

Teachers in my community give the students who have a hard time learning more time to do assignments and a little more help if they aren't busy. Teachers need to learn how to show these students how to do things before sending them off to do their homework.

Alicia, YOUTH ADVISOR

ents who submitted stories to IHSTS told us that at such times, their children were punished or blamed for being deliberately disruptive. Parents stressed that their child's acting out behaviour is not the failure of the child; instead, it is the failure of the adult, who did not respond to the child's needs with patience, understanding, calm and skill. But it is also a failure of the system for not properly supporting the adults in the classroom environment. We believe that such failings would be dramatically reduced if children on the autism spectrum had access to educators and educational assistants who were adequately trained, skillful and consistent in their responses to these young people and who could help give them a sense of predictability and control over their environment.

Teachers are ideally placed to speak out on their behalf. Teachers also need to help these young people learn everything they can about how to function in life, live in the world and develop the skills to live as independently as possible when they reach adulthood. In other words, teachers need tools to help children and youth with special needs "own their own lives."

"We want our teachers and other children to understand special needs."

Students with learning disabilities told us that no one explained their "learning disability" to them so they never understood that their way of learning was different from their peers. Without this awareness they just felt that something was "wrong" with them or they found themselves isolated from their peers and felt "stupid." This fear of being "different" became a cause of failure on its own as they struggled with why it took them longer to learn when their peers seem to learn so easily.

I love school. I was always a very social kid. I made lots of friends, and kids would fight over who would get to push me around the school. Elementary school was a good time. High school, grade 9, was more difficult. Most of my friends who I was really close to went to a different school than I did. Then I had trouble in grade 9 making friends. I was the only student they had who had a disability and was in mainstream classes. I was in all academic level courses. I think some of the teachers had never really interacted with a student with special needs before. I remember the first teacher on the first day of grade nine said 'What are you doing in my class?'

Nicole, YOUTH ADVISOR

"We want better accommodation in school."

It was apparent from reading the submissions that the word "accommodation" can have a different meaning for every child or youth with special needs. For some, accommodation was about needed some adjustment to the classroom environment itself. For others, accommodation was about changing the curriculum to match how a student with a particular special need learns. For others still, it meant adapting the curriculum to fit around the unique skills, strengths, needs and abilities of a given student, not their diagnosis.

What seemed common in the opinions of those who wrote to us was the importance of taking an individualized approach. For example, there is no point in insisting that a young person who cannot read take a multiple choice test and "accommodate" them by putting them in a separate room or giving them more time; they can't do the written test and should be able to give verbal answers.





Sammy

"There is a darker side with the learning disability. I wasn't in a mainstream classroom. I got diagnosed in grade 3. So from grade 3 on I was in special education. I don't think I knew that I was different in that sense or that I needed extra attention. I don't know if it was intentional or not but it was kind of hidden because my special education teacher wanted me to wrap up my textbooks in wrapping paper. The reason I was told was, 'They're new, we don't want to ruin them'. Thinking back now, how weird was that? I understand the reason for special education, and I believe in inclusion as well, but it's a grey zone for me. Because when you put a child in special education you're targeting them already and they have to work at low self-esteem then. They have to work through them being different. Sometimes not even knowing the reason why they're in another classroom. But then if you put a child in a mainstream classroom without those resources you're not working in the best interests of the child either. So I

think it has to be a combination of both.

I think it would have been an easier transition between different school systems if [my learning disability] was explained [to me]. I went through my whole education life thinking I was stupid, because it was never explained. This affects my self-esteem. Every time I make a mistake now I always second guess myself. It must be the disability. It must be this. So OK I get good grades now. I remember the first time I got an A. It was grade 7. I was the only one that got an A in that class. The teacher announced it and everyone in the classroom turned around, because I used to sit in the back, and looked at me in shock. Thinking back I think why? Did they think I was stupid too? There needs to be more of an understanding of what a learning disability is. Because it's not about IQ. Even though I'm in graduate school today, I still can't believe that I'm that boy in grade 7 with that low self-esteem."



Joy

"It was really hard, because the school didn't see Joy's challenges completely. Joy was diagnosed with FASD, and she struggles. She needed school to be caring, more in tune with what her needs were. They viewed her as just another student who didn't matter and was disruptive to the class. They viewed her as a pain in the butt student. At one time we setup a safety plan for Joy. If she was feeling unsafe, or a risk to herself, she was able to go straight to the principal and they would let her use the phone. One day when she needed support she went to the principal's office to try and use the phone and they said she couldn't do that, they were

too busy, and so she ended up in the bathroom harming herself. I talked to the principal and said 'the safety plan you helped put in place failed her.' To the point where we ended up getting the police involved and said this is serious stuff, you guys need to know where she is all the time. You need to keep an eye on her."

—Randi, MOTHER OF JOY

What do you see?
What do you see, teachers what do you see?
Are you thinking when you are looking at me,
A lazy student who doesn't even try.
Never finishes his work you wonder why,
Even if it's done it's not handed in on time,
Who procrastinates so much you'd think its a crime,
He is always late and never prepared,
He misses instructions like he's hearing impaired,
He is always getting distracted it must seem like he doesn't care.
Is that what you think is that what you see look closer teacher,
Look closer when you think of me,
I was born with a disability called ADHD,
This isn't an excuse it's just a little about me
I'm unorganized but I'm getting better,
But however large the setbacks it's a worthwhile endeavour
My fine motor control is poor but my writing is strong that is,
Unless I procrastinate too long.

—Charlie, youth. POEM CONTAINED IN YOUTH SUBMISSION.

Rana



"High school was the first low point in my life. Before that I had a great time in school. The last part of elementary school was amazing. Then high school was rock bottom dreadful. All these incidents kept piling up with all these teachers and educational assistants (EAs). For example, one thing was, the teachers wouldn't talk about my marks with me. They would go to the EAs and then the EAs would talk to me. The EAs are there to support you – not be a teacher to you. It wasn't like I didn't know what the teachers were saying or that I couldn't understand. That was the stigma of the special need; the

teachers would not speak to me directly but go to the EA and ask them to talk to me. It made me feel pretty bad.

At the age of 16 you should be able to manage your own stuff. But they took that away from me. These people, who I barely knew, learning about my personal stuff like marks, without my permission or consent, and then discussing this with the teachers. That bothered me. It was unethical."

Fast Facts about special needs and education in Ontario

Ontario has the largest gap of all provinces in literacy scores between cognitive or emotionally disabled and non-disabled students.¹

Ontario has the third lowest rate of special needs students in regular classes.²

In every province, close to one third of parents of children with disabilities report difficulty in receiving special education services. The proportion was highest in Ontario.³

1. Source: <http://www.statcan.gc.ca/pub/81-004-x/2007001/9631-eng.htm>.

2. Source: Ibid.

3. Source: Ibid.

In my community most students have disabilities. I can tell by their body language in class or in the school in general. Most students don't go to their classes because they have sensory issues and don't like being in a crowded classroom and prefer to be on their own.

Alicia, YOUTH ADVISOR





Grade 1, 2 and 3 teachers called special needs students in my children's classes, (including my own children) "bad", "lazy" ripped up their work, yelled at them, made ignorant comments about their parents and did nothing to help them.

Jennifer, PARENT

"Don't treat us harshly for being who we are."

According to the stories of young people who made submissions, the frustration some teachers or educational assistants felt when they could not manage their students' behaviours were expressed through the use of harsh words spoken to the young person in front of other students. Being treated this way for something over which they may not have any control felt humiliating. In the opinion of some, this reaction on the part of teachers or EAs comes from a lack of experience, training or understanding about students with special needs.

One particular special need that appears to attract harsh treatment is autism according to a number of submissions from young people on the autism spectrum. This kind of treatment should never be used on children within the spectrum because they often cannot associate consequences with their behaviour. More than that, punishment does not teach appropriate behaviour.⁵

5. Source: <https://www.autismspeaks.org/blog/2014/08/15/physical-discipline-autism-parent-asks-guidance>.

Children on the autism spectrum

1 in 68
children is on the
autism spectrum.

The prevalence of ASD has increased over 100% in the last 10 years. Autism is now the fastest growing and most commonly diagnosed neurological disorder in Canada.¹

80%
of people on the
autism spectrum are
unemployed or
underemployed.²

1. Source: <http://www.autismspeaks.ca/about-autism/facts-and-faqs/>.

2. Source: Ibid.

Parents expressed frustration and anger that their children were judged or criticized by any adults at all. We heard from families who complained to principals but that their actions rarely resolved the problem. We also heard that the process for dealing with what parents saw as unprofessional, unfair or discriminatory behaviour toward a child with special needs tended to be biased in favour of the teacher. We heard that education staff were rarely disciplined for their behaviour in these incidents and remained in their positions, continuing to do a poor job with these children, creating fear and perpetuating learning environments in which children felt unsafe.

It's understandable that poorly trained, over stretched and under supported teachers and educational assistants get tired and stressed.

Unlike other students, I had to worry about more things than academics and social life. I had to ask each university about the resources they provided for students with disabilities... Some of the institutions appear to view their disability services as an afterthought for students and one which students thought about only after applying to their school and even after arriving on campus.

Hibaq, YOUTH ADVISOR



It's kind of hard trying to understand things. There were a couple of teachers who understood and knew how to explain things better than other ones. They knew that explaining in different ways was a lot of help. They explained things, like what each word meant. Some of them know how to work with certain students, and other ones don't.

Brandon, YOUTH ADVISOR

But they too must understand that the use of criticism is not an effective way to get students with special needs to respond in a positive manner. Teachers, educational assistants, principals and all staff working with children on the autism spectrum must take time to understand how these children learn and what they need to feel safe and supported.

"Put us at the decision-making table in schools."

Children and youth frustrated by their learning disabilities reported that they just "switched off" and stopped trying. Too often, this resulted in poor treatment from a teacher, which further compounded their difficulties. Frustration—indeed, any behavior that shows a student is disengaging from learning—should be an indicator that the form of instruction is not working for that child.

We heard that rather than reacting as though there is something "wrong" with the child, teachers or educational assistants who are able to recognize they are struggling to meet the special needs of their students should stop what they're doing, talk to the student and find the best way forward together. This dialogue should be ongoing. Teachers must routinely ask students if their learning pro-



gram is working and, if not, what could help change the situation. More than that, students should have more say in the development of their independent education plans (IEPs). Children generally know themselves best; yet most are never asked for their input or opinions.

Listening to the experiences of young people with special needs we think it would be helpful to include them in decision-making beyond the classroom and that all school curricula should be examined through a special needs lens to see how it may be made more flexible and adapted for students with different learning styles. One very interesting suggestion we heard pertained to the setup of gym class so that sports activities would be designed to ensure that students with special needs were not left simply sitting on the sidelines watching.

"We want safe and welcoming learning places."

Many of the young people and parents who sent us submissions said that creating welcoming and safe learning environments—and providing educators with the skills needed to make it happen—should be the number one job of schools. Children who didn't feel emotionally safe couldn't learn, partly because unsafe classroom environ-

The teacher always wants to go through other staff to get to me. I wish they could come directly to me. They interpreted my individualized education plan without asking me. The student's voice is not heard at all. They think our needs will be a burden on them.

Rana, YOUTH ADVISOR

It feels really hard. If I am reading a book and I read the first sentence, I understand. But paragraph after paragraph it gets more difficult. Since grade one it's been really hard, because no one understands what I am going through. My family and my sister understand, but people from the college don't know what I'm going through. They don't help me at all. They just want me to drop out.

Parul, YOUTH ADVISOR

ments compromised their ability to trust. We heard a great deal from parents who often had to struggle for hours just to get their child ready or willing to attend school each day—only to have them go into an environment they experienced as hostile and unwelcoming, where their peers teased or taunted them or in which they could find no emotional support. This issue points to a requirement for more manageable class sizes and more training and support for teachers and educational assistants to create supportive learning environments for all students.

We were told that unsupportive classrooms can create for some young people with special needs, a view of the world where they dislike other people or don't want to be around them, a situation that is the opposite of what they need to grow and develop. When schools felt unsafe or unwelcoming they caused students with special needs to begin seeing the world outside of their home as being hostile which affected their emotional development and robbed them of the ability to socialize and make friends. At a most basic level, the creation of safe, supportive learning environments was as important to them as any other aspect of their education.

We heard from young people and their parents that greater attention needs to be given to making classroom settings cleaner for medically fragile students and ensuring that all materials in the learning environment are accessible to students in wheelchairs. Many reported experiences such as being given a separate gym class or being excluded from field trips because including them was “too complicated” or “inconvenient”. These exclusions were more than just hurtful. They negatively affected young people's educational achievement and contributed to lasting feelings of worthlessness and inferiority.

But the problem can be even more pervasive than that. When the classroom environment does not meet the needs and abilities of these young people, their academic performance can fall well below their capabilities. If little is expected of them, little is achieved.

The worst situations young people spoke about seemed to involve being humiliated when educational assistants or teachers were im-

People didn't really accept me at school. A lot of EAs and teachers weren't treating me very well. I didn't come to school much. And I was one of those kids that was, you know, I had a negative attitude about school, and a lot going on at home. And the kids would bully me. Yeah, I kind of went through that stage where I was slipping through the cracks and nobody was really doing anything about it.

Falum, YOUTH ADVISOR



Education should involve a variety of approaches rather than a single approach because everyone has different ways of learning. Last year, in grade 12, I was really stressed out and I asked the teacher to reschedule my presentation times. They had a conversation in front of the whole class about my individual education plan and accommodation. They always wanted to know what I was doing even though they didn't have to know. I wish I wasn't scared as much as I was, but I was.

Patrick, YOUTH ADVISOR

I got bullied quite a lot. When sent to the office, the students would lie to protect themselves from getting in trouble. But, ironically, the student who bullied me received the honesty award from my school, even though they lied.

Cameron, YOUTH



**I believe that we
should have schools in
Ontario that help kids
like me. It is hard for
me to go to my school
because I feel like I
just don't fit in,
because I don't
understand some
things and I don't
feel like people
understand me.**

Justin, YOUTH

patient with them in front of peers. They told us they often are not treated the same as their peers. This poor treatment caused them embarrassment. They felt that the adults in their lives need to be more aware that they are setting examples that will guide how other students see them throughout their school lives and beyond.

"Please protect us from bullying"

Another issue mentioned frequently in the submissions was bullying. Many students with special needs were picked on because they were considered "different" by their peers. Complicating matters were situations where school officials had to decide whose story about what happened in a conflict between students was true—the bully or the victim. In the absence of witnesses to support one young person's side of the story over the other's, we heard that principals would



It depended on if the teacher understood what Brandon was dealing with and how to engage him, because he has to be engaged. You have to build that relationship with him. Otherwise it doesn't work. If you don't do that, then you don't have much of a chance to teach him.

Debbie, PARENT

simply drop the matter leaving the bully free to continue to causing harm. Also, bullies can often avoid punishment when they're better at manipulating the conversation about what happened in a conflict and make it appear that the student with special needs was the instigator.

And it's not only peers who bullied these young people. IHSTS received submissions claiming that educational assistants or other school personnel at some schools had been verbally abusive toward students with special needs but that collective bargaining agreements made it difficult to remove these individuals.

Young people made it clear in their submissions that they want inclusive learning environments where they feel safe and can be a part of school life, interacting positively with peers and reaching confidently toward their dreams and goals. Young people with special needs told us they just want to have fun and "do things" like everyone else their age. But to do this they needed teachers to ensure that they

The educational assistants would act so nice to me in front of my parents and then interrogate me after my parents left. It would happen almost every time. Hierarchy in EAs makes them in control and power.

Rana, YOUTH ADVISOR

**The grade 8 class
was not safe for me. I
could not do my work
and was bullied,
and had thoughts
of suicide.**

Joy, YOUTH ADVISOR



**My foster sister has a
special need because
her mom drank
when she was in her
tummy. She was in
so many homes and
they treated her bad
so she came to us.
She's very nice, very
good and helps me
a lot. Sometimes she
hides behind her face
and doesn't talk. But
when she gets used
to people she'll talk
and is funny. She likes
to have fun and laugh
with her friends. She
needs more friends,
good friends who
aren't mean to her.**

Kristine, YOUTH ADVISOR

don't get bullied and they need all adults to respect their privacy by ensuring discussions about their needs are conducted out of earshot of the other students.

"Having a friend changes everything."

When young people have complex special needs, professionals tend to "medicalize" their lives and the management of their health becomes a primary focus of young people's interactions with the world outside their homes. This might also lead to professionals seeing these young people as perpetual children instead of people who are developing into young adults.

Peers are a key part of socialization and childhood development. When children and youth with special needs lack the opportunity to socialize, this seriously compromises their development by curbing their opportunities to date, form intimate relationships and explore their sexuality. We heard that when the adults around them become single focused on medical or learning needs, they forget how similar these young people are to other youth—and how much they want similar lives.

Young people told us that they just want to socialize with their peers or friends but can't because of the equipment they sometimes depend on: Who is going to lift them in and out of cars or help them navigate the transit system with the rest of the group? They don't want to have to book special needs transit two weeks ahead, they want to be able to get to the party tonight.

Braedon



"I am 12 years old and have ADHD and a learning disability. Spelling is really hard for me. It is also really hard for me to sit still in class. Sometimes I get in trouble at school. When I was younger I used to go and see a special teacher who would help me with my reading and writing. Now that I am in grade seven, I don't go and see him anymore. I wish I could still go. School would be a lot easier for me if I could use the computer to do my work. It would also really help if

I could take breaks from work and go to a quiet place. I'm a pretty shy kid so it is hard for me to talk to my teachers about these things. I like spending time at the community centre. There isn't pressure to act or be a certain way. I get to just have fun with my friends. I wish school could be more like that."

At my old school I was left out because no one wanted to hang out with me because I wasn't like them. I was not getting along with others. I started scratching, hurting and yelling at people. I am happy now. I keep up with my work. The teachers explain things differently and I understand. I know that I learn different from others.

*Walter, TEACHER ON BEHALF OF
A STUDENT WITH SPECIAL NEEDS*

Like all young people, youth with special needs told us they want friends to do things with—simple things, like going to a movie or just hanging out. They want the opportunity to make lasting friends—not just have other students who say “hi” in the hallway then ignore them the rest of the time.

One idea we heard was to include in the Ontario curriculum opportunities for students to learn the skills they need to make friends and build a sense of connection and community with one another—including with students who have special needs. This could include learning about various types of special needs and what they could mean for the child who has them. The more connected students are to one another, the less likely that bullying and segregation will result. No student should be “left out” or feel alone. Such segregation marks a failure of the school, not a failure of the student.

We heard from young people that school success—even the very desire to go to school—is positively influenced by the presence of friends and peers at school capable of providing them with emotional support. Also, when adolescents are establishing their identity as individuals, peers are essential in a student’s process of trying out different aspects of personality. Young people with special needs often miss out on this stage which enables them to separate in a healthy way from their parents and families.



Some young people struggling with complex needs found it hard to connect with other youth and therefore hid behind “walls”. But the intention may be more to hide from judgment or stem from feeling scared, as opposed to wanting people to really stay away. Children and youth with special needs are clear that they want connection. They want friends. But the world can be anxiety provoking for those who feel fragile or different.

“We want to involve our families and supporters in the learning process.”

The families and young people who wrote to us spoke repeatedly about the struggle they had finding the right supports for their school-aged children. In their submissions families wanted us to know they often have to do their own leg work to figure out how to obtain an early diagnosis for their child and locate the support systems that will work best for their child in their specific communities. We heard from parents who have to advocate constantly on behalf of their children in the face of unsupportive school staff. Some students with special needs required significant medical support but schools were unwilling or unable to accommodate them.

We see in their words the need for better coordination of all the people, programs and opportunities available so that each child receives the education that is their right. We rarely heard of situations in which a student with special needs received all the support and assistance they needed to succeed. Instead, parents struggled to stitch together all the pieces that could find to make their lives and the situation of their child tolerable within a confusing and unhelpful education system.



At one point the conflict got so ugly the Superintendent of Special Education was yelling at us and our advocate in an IPRC meeting because we had pointed out our son's principal was making statements that our son was falling behind academically — but the report cards she was signing indicated steady academic progress since grade 1 and that he was meeting his goals.

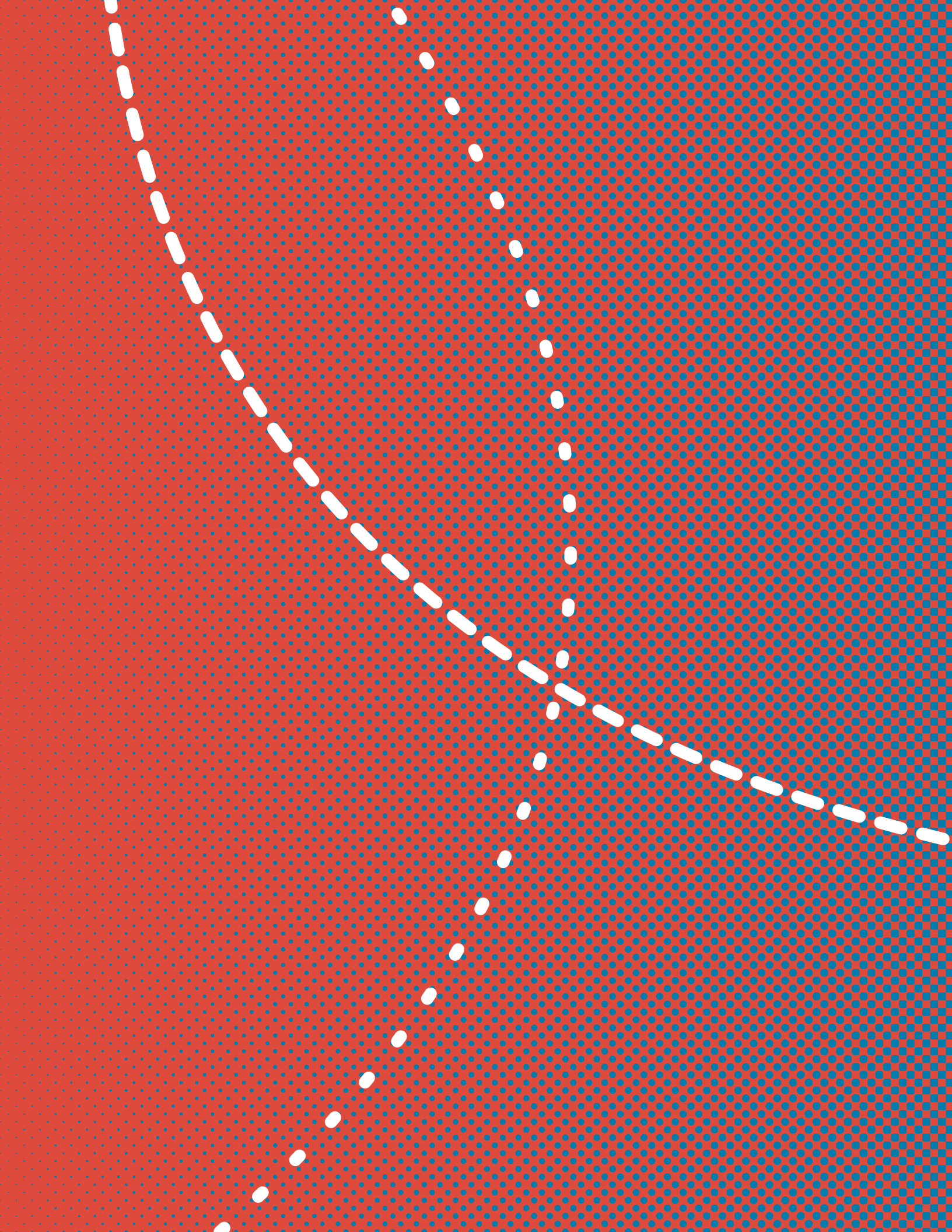
Tyler and Laura, PARENTS

RECOMMENDATIONS

SCHOOL AND ----- EDUCATION -----

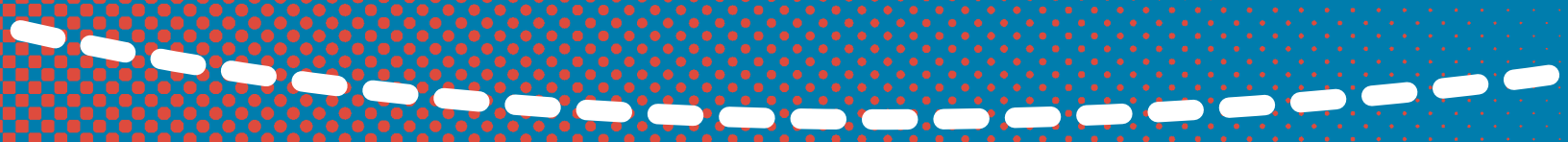
- 1.** The Ministry of Education must establish a youth advisory table and on-going working partnership with children and youth with special needs to inform and review policies pertaining to all facets of their education.
- 2.** The Ministry of Education must work with the youth advisory table to develop content for in-service training for all school personnel who work with students with special needs. Principals, teachers, educational assistants and administrative staff must see students with special needs as individuals with unique strengths and differences and be respectful and supportive of those unique strengths and differences.
- 3.** The Ministry of Education must work with the youth advisory table to develop curriculum—beginning in the early grades—that normalizes difference, helps reduce stereotyping and eliminates bullying. This curriculum must help students develop the skills necessary to establish friendships across difference. This skill-building is needed to help all students, including those with special needs, see themselves as part of a supportive, welcoming and interdependent learning environment.
- 4.** The government of Ontario must ensure that all children who need it can get timely access to effective assistive learning technology and that this technology be kept in good repair and up to date.
- 5.** The Ministry of Education must use a special needs lens to ensure that all policy and curriculum is designed with the goal of ensuring that all students can participate equally in all learning activities.

- 6.** The Ministry of Education and the Ministry of Colleges, Training and Universities must ensure all schools, colleges and universities are fully accessible. This includes maintaining barrier free access to sidewalks and walkways and entrances in all seasons. It also includes the accommodation of students with electric wheelchairs, service dogs, personal support workers, communication devices or other required supports.
- 7.** All student teachers must be required to spend a portion of their professional education in a special needs learning environment. Upon graduation from teachers college, educators should be prepared and able to work with students with special needs. College instructors and University professors and administrators must be required to have the knowledge and supports to accommodate students with special needs.
- 8.** Students of any age or ability must be directly involved in providing input into the development of their Individual Education Plan (IEP) and participate in the Identification, Placement and Review Committee (IPRC) meeting that determines whether or not they need to be identified as having special needs.
- 9.** Universities, colleges and all post-secondary training programs must provide information on disability services and summer transition programs to all students in their acceptance packages.
- 10.** The Ministry of Colleges, Training and Universities must develop and work with a youth advisory table with the goal to review eligibility criteria for admission, grants, student loans and bursary programs.



SECTION 3

Supports & Services





SUPPORTS AND SERVICES

A high and disproportionate number of human rights complaints are made by or on behalf of people with special needs. Many arise as a result of people not receiving the supports and services available to them in Ontario. The Advocate's Office considers this situation unacceptable. We can do better and government and the service system must begin working in partnership with young people and their families so that children and youth with special needs are released from the continual struggle to obtain the supports and services to which they are entitled.

Young people, families and supporters who made submissions to IHSTS envision a more coordinated system in which support services are available and accessible, and in which funding is sufficient to provide the level of care needed by young people with special needs. They also want supports to be more flexible, proactive and directed by the young people and families they seek to assist.

"Give us a user-friendly system that works."

The submissions we received spoke loud and clear: Ontario's system of support for children and youth with special needs is not working. A major concern we heard is that families are being forced to absorb many of the costs of providing the care their children are entitled to. Families are constantly struggling to find support and assistance for many urgent areas of need. Often, this is happening to the most vulnerable families who are least able to absorb these extra and costly expenses. In many cases, families are required to pay upfront for respite services, specialty camp fees, medical equipment or other costs then submit claims to the government for reimbursement. For families living pay cheque to pay cheque, there simply isn't the money available to do this so needs go unmet. While waiting for reimbursement, families may run out of money to cover rent, utilities or pay credit card balances, thereby incurring interest charges or late fees.

The issues for young people with special needs are diverse. Some of their families require financial assistance with physical supports such as appropriate or modified housing, special equipment or devices to provide care within the home or technology to help non-verbal children communicate. Others need easy access to basic medical supplies such as bandages. Still others require funded services such as day programs important for meeting the developmental needs of their children, mental health supports, resources for obtaining

When you're first diagnosed with something, you get a package saying here's what numbers to call, this is what you can deal with and then you're on your own. There's really no one to help you. You have to call, you have to navigate your way. Nothing is under one umbrella. It's here, there, everywhere. What's federally funded? What's provincially funded?

Anonymous, PARENT

Inappropriate supports for individuals who have extra support needs is a core issue... start to think about supports to individuals using a broader, more community-based, naturalistic and inclusive model.

Margarita, SERVICE PROVIDER



assessments, therapy and medication for young people with complex medical or mental health needs, better access to counseling, more speech and occupational therapy—the list goes on. Young people want to know why it is so hard to get the help they often desperately need.

Another major challenge raised is that many young people with special needs and their parents are not clear about the process involved to access available services. In a large number of the submissions, we were told that parents simply did not know where to turn for assistance. They desperately needed help to navigate a complicated service system. Because they do not know what assistance is available or how to obtain needed supports and services many children and youth simply do without.

We heard candid stories from loving families of children with significant special needs or complex health or behavioural issues who had become so physically or mentally exhausted themselves, or financially depleted, that they were considering moving their children into the care of a children's aid society. These families would benefit greatly from case managers who could help them navigate the complex system of supports and obtain the help their children needed. Unfortunately, access to effective case management is not equitable across the province, so many families fall into crisis before they can get the respite or other urgent support they and their children need.

We heard from one mother who experienced lasting mental health impacts from having endured months of unending physical and psychological stress after the birth of her premature twins who had special needs. She was overwhelmed but did not know where to turn to help find respite and the supports and services she needed to provide the level of care her children required. This and other stories contained in the submissions make it clear that at the core of the system there is a lack of focus on supporting families in a holistic manner according to their specific needs and circumstances.



It would be nice if we had a break, and less trouble getting what we need. No need to argue with anybody for the money to get the bandages. No need to argue to get the things I need for school. We were trying to get a vibrating bed for my bones. My bones are running low (less dense). It's very expensive, and we don't have the money. So, that is what we need, for life to be a little easier.

Jonathan, YOUTH ADVISOR

I would like to say that people with FASD and their families need MUCH better supports.

Nancy, PARENT

**I had a lot of injuries.
A few black eyes, a
bloody nose and stuff.
He just grew bigger,
stronger. A year ago
it was just becoming
every day. He'd
either be lashing out
or he'd be sobbing
uncontrollably. Not
much in between. I
knew I needed help
but I didn't know
how to get it.**

Kerry, PARENT

**You see so many
different doctors. You
see so many different
specialists. We've
been bounced around
based on our postal
code alone, or we
get downtown and
we're told we're not
supposed to be here,
we're supposed to be
over there.**

Anonymous, PARENT



"We need a more accountable approach to services and decision-making"

Some families of young people with special needs told us they were being driven into poverty because of having to subsidize the cost of providing care to their child. Tragic situations like this could be avoided if there was a more helpful coordination of services to link parents to financial supports that were available to them.

Many young people told us they felt left out of their own lives because the decision-making that affects their care and the quality of their lives is being made solely by parents – who may not agree with or understand their child's personal wishes – or service providers who don't understand their needs and daily lived experiences. Young people also explained in their submissions that front line service providers, who do have the experience and deep understanding of what they need, are not being consulted enough by their teachers or other service providers who provide them with care.



Tiffany

"After Tiffany finished high school it was recommended that I take her to the Dryden Association for Community Living. I took her there a couple times. I would drop her off, and she would spend the day there while I did whatever I needed to do. The last time I had Tiffany over there my son came with us. We took Tiffany in there, and when we left my son said to me 'Why are we taking her there?' I said it was because she does not belong at high school.

He didn't know how to put it, but he knew community living wasn't for Tiffany. She had a life before the accident. He was really bothered by the fact that Tiffany was being blended in that way. It upset him so much that she was being categorized, I guess. He was offended by that. After that I never took her back there.

Now I guess what I am saying is that there is no facility or anything like that in the area

that would be for somebody that has brain injury. Right after the accident, I was really hard pressed to get any kind of information or reading material. I wanted everything there was to know about brain injuries. It wasn't something you just go out to learn. The only thing I could get was a few pamphlets. There was a library, because the health sciences centre in Winnipeg, the university is right next door. That's where the library is. So I went over there and I ordered a couple of books. Those took so long to come. I went down to Chapters and ordered some more books. I was just reading everything, and it just struck me why there isn't information about it?"

—Della, MOTHER OF TIFFANY



I think there is a lack of government oversight. Although MCYS provides funding to many respite care centres, they don't ensure that qualified nurses are actually sent. They don't have adequate training.

Anonymous, PARENT

My son's adaptive functioning is extremely low, but his articulation and intelligence is very high. He will not be able to have a job, live independently or experience activities without effective support of a person who understands his disability and calmly helps him through situations.

Wendy, PARENT

Young people and families want to see a more unified and accountable team approach to the delivery of services so that they are not continually scrambling to find or obtain the care and assistance they need. Many of the IHSTS submissions called for support that is collaborative, community-based and inclusive. For example, a collaborative approach would enable teachers and others not directly connected to services for children and youth with special needs—but who nevertheless must manage the special needs of students from time to time—to learn from service professionals and obtain crucial knowledge and greater understanding of what they need to better support their students.

We heard that the current maze of poorly coordinated systems can set young people and families up for failure, and that when promised services are not provided, nobody is accountable. In the experience of young people and their families there is more that government and the system needs to understand about the day-to-day challenges faced by children living with special needs in order to reduce gaps in service. Young people with special needs and their families dream of a system of supports and services with interdisciplinary teams that are educated about their unique needs and who can help them make more independent choices concerning their lives. In their submissions young people simply asked for a system that respects their rights and is accountable for providing the supports and services they need and to which they are entitled as citizens of Ontario.

Children and youth with special needs told us they needed coordinated supports that included respite care. Older youth required help finding appropriate housing and personal support workers.

"We need higher standards of care"

Young people and their families told us they felt many support workers need better training and more supervision. They said they were concerned that support for young people with disabilities relies too much on 1:1 care. Such care can be sub-standard or even harmful to a child with special needs if the care worker lacks proper training, education or experience in working with this youth population. For example, lack of training can result in a child being touched without their permission (even when the touching is a necessary part of their care) or without the appropriate level of attentiveness and gentleness that many children with fragile medical or other special needs require—especially young people with severe disabilities who may be non-verbal. We heard clearly in the submissions that highly vulnerable young people need to feel safe.

One specific concern we heard was that professionals have a tendency to “speak over” young people who have special needs or speak about

As a parent who has to fight for our legal rights, I am tired of cliches. Will our story actually contribute to ensuring a fully inclusive society? Will decision makers be held fully accountable when they manipulate, exploit or deny the rights of children with special needs? Will my family and other families no longer be pushed to the corners of society, face a life of poverty, face increased victimization and have other privileges denied?

Katherine, PARENT



Applied for ODSP and they say that my IQ is too high. People with autism have a higher IQ. I appealed it and they said I will grow out of it. They need more training and to understand us.

Aly, YOUTH ADVISOR

Bloorview's motto is: from disability to possibility. An example in high school, the educational assistants wanted me to use a power wheelchair because it would be easier for them to help me, but I wanted to walk because that's the only exercise I got.

Rana, YOUTH ADVISOR

I would like to see a sense of community... or somewhere I can go where if you wanted to go to a park, it was accessible.

Anonymous, YOUTH



the youth while they are present instead of speaking directly to them. We also heard stories about staff that are unqualified and irresponsible, sometimes putting the physical safety of young people in their care in jeopardy. In such cases, parents' complaints were generally futile, as there was no accountability mechanism available to them.

Families want agencies that manage personal care workers to be held accountable for the level of professionalism, awareness and skill they bring to the job of caring for young people with special needs. Families also made the point that accountability is meaningful only if their children are able to communicate their views back to service providers. Support and service organizations who serve young people with special needs must operate according to standards and quality service benchmarks determined in conjunction with the children and youth who use the services.



"Let us in!"

Despite the well-intended efforts of government to make Ontario more accessible through the *Accessibility for Ontarians with Disabilities Act* (AODA), comments made in the submissions reflect that in the daily lived experiences of many young people and their families more work remains to be done.

Young people told us that they had difficulty accessing washrooms, stores, restaurants, and places offering entertainment or leisure activities because of physical barriers such as inaccessible buildings or sidewalks that are not passable in winter. In fact, the most common complaint regarding accessibility from all people with special needs in Ontario is inaccessible buildings.¹

1. Source: Monsebraaten, Laurie. "Ontario needs to boost accessibility efforts." *The Toronto Star*, 13 Feb. 2015. Available online at: <http://www.thestar.com/news/queenspark/2015/02/13/ontario-needs-to-boost-accessibility-efforts.html>.

I am advocating for change at a system level. I envision mental health supports within the neonatal intensive care units or children's hospitals in order to enhance parental resiliency and attachments. Additionally, an integral component of such support must occur during the transition home and following discharge.

Christine, PARENT

Jeepers, people that have stores and buildings: LET ME IN! There are steps and cracks and the brand new MC Cafe in Kemptville has no outside accessible button! I just helped make a video for Kemptville Youth Centre to raise funds for a special bathroom and ramps.

Jake, YOUTH

We received stories from young people who were unable to get into buildings in their neighbourhood or ride public transit because of accessibility issues. In one submission, a young woman reported that half of Toronto's subway stations have no elevator and are therefore inaccessible to her. This is poor performance in a province that enacted accessibility legislation, the *Accessibility for Ontarians with Disabilities Act*, 2005, more than 11 years ago. Outside urban areas or in rural, remote or isolated communities, public transit is non-existent so young people with special needs often remain stuck inside their homes.

Young people with special needs informed us they wanted to see accessibility measures such as special seats in planes, buses, trains and other transportation vehicles so that their harnesses can be accommodated. They wanted bathrooms that are accessible not only inside buildings but outside in public areas. Young people asked for playgrounds that are accessible and inclusive for children of all abilities.

I want accessible washrooms to truly be accessible more supports so I can live independently. I want accessible sidewalks. I want to be heard.

Anonymous, YOUTH



The submissions contained a call for greater public awareness of young people with special needs. They drew attention to accessibility and how things as simple as deep pile carpets in social service settings, government or private owned buildings, treatment settings or residential placements can create problems for mobility.

“Please support us in our homes.”

Home support is a key resource for young people with special needs. There was consensus in the IHSTS submissions that families and caregivers require more supports overall, including respite care, to help them provide the care their children need in the environments where they feel most safe and nurtured. Home provides an optimal environment for children and youth with special needs because it provides access to the very things young people need—the emotional, cultural spiritual and connection that comes from family. It’s also less costly than providing care in large and impersonal institutional settings. However, to provide this care at home, young people and their families must have access to the equipment and other supports they need.

Families requiring around the clock care for their child expressed being caught in a desperate struggle for support. For example, children with respiratory issues often need constant monitoring. Children with tracheostomy tubes are especially vulnerable. They need awake and alert caregivers 24 hours a day paying attention to potential blockages and the need for tube suctioning. With the maximum number of nursing hours currently provided by the government at 43 hours per week, that leaves 125 hours of constant and attentive caregiving that must be provided by parents. This level of stress and attention, often needed during the night, can leave parents and exhausted and ill themselves.

Young people also let us know that the supports provided outside the home they needed would be more helpful and effective if they were “naturalistic” or less “institutional”. Institutional settings rarely convey any feeling of “home” and can be frightening environments for fragile children. They make them feel like a “patient” not a whole person. They also want easier access to care and to be referred less, as every new referral can result in long wait times and slower progress in their treatment. They made it clear that “referrals are not a substitute for badly needed service.”

Government Funds For Special Needs Left Unspent

**Since 2005,
\$24 million**

in government funds earmarked to oversee the implementation of the *Accessibility for Ontarians with Disabilities Act*, 2005 remained unspent in 2014. At the same time, about 70 per cent of Ontario businesses with 20 or more employees – about 36,000 – were ignoring provincial accessibility laws.¹

1. Source: <http://www.peoplefirst4aoda.com/ontario-businesses-ignore-provincial-accessibility-law/> pg 1.

I started using the regular Toronto Transit Commission (TTC) in November after I used Wheel-Trans for two months and got tired of it because there were issues. I had a project to talk about TTC: only 34 of 69 stations have elevators.

Rana, YOUTH ADVISOR



The fact that they didn't know I was autistic until I was in grade seven, that was really hard. Having (a diagnosis) at like 3, like they're doing now, maybe I wouldn't have had as many difficulties with learning and social skills. Maybe that part of life would have been easier if I had been diagnosed earlier. If someone had only paid attention and noticed and gotten me some help.

Aly, YOUTH ADVISOR

Especially for my mom, there was not enough support...In the younger years, it's not that bad. But once you get to grade 7 and 8 and high school, you get more hours of homework. There are only so many hours in a day. I think it would be helpful if somehow my mom could get compensation for all the work she did. Trying to work a full-time job, raise two kids, one of which has special needs. Until I was about 17, we used to go to my dad's place every other weekend. So I guess she got a little bit of a break. But, one weekend every two weeks isn't enough.

Nicole, YOUTH

Through their submissions, young people expressed a need for funding to help them overcome the barriers that prevent them from participating in “fun things” like summer camp, music programs and other activities in the community. These opportunities for social interaction with peers add significantly to their quality of life. It’s a simple matter of equality; young people want the same opportunities to go out and “do things” that are enjoyed by their peers. They expressed a need for more services that support independent living that, in turn, can lead to more opportunities to socialize and participate in community life.

Everyone in society needs a sense of connection and belonging to others in order to thrive. The situation is no different for youth with special needs. Strong support is required to prevent secondary special needs from occurring such as mental health challenges brought on as a result of being isolated from community life and normal social contact or interactions. The same goes for families. In their submissions, parents expressed a desire for more opportunities to meet other families who are raising children with special needs to learn about their experiences, share knowledge about resources and offer one another a sense of community and connection.

“Please help us early in our lives, when we may need you the most.”

We heard from young people that the supports and services they receive are only as good as the diagnoses they receive. Diagnosing children with special needs and intervening early in life is essential to ensuring they receive appropriate and effective services and resources.

In the IHSTS submissions received from families of children who have a diagnosis of autism (ASD), we were told that delayed diagnosis and delayed treatment are common in Ontario for their children. Many were continuing to struggle to obtain a diagnosis for their child. Others stated that even when a diagnosis was obtained, a new struggle began to find and access publicly funded treatment.

We heard from families that there is need for access to more and better diagnostic criteria for children with fetal alcohol spectrum disorder (FASD). Families who adopt children with FASD can ultimately take on a large burden because FASD is not necessarily apparent in a baby. If adoptive families had more information about their child at the point of adoption they could pursue early intervention supports and services to help their child lead a better life.

Our children with special needs must be made to feel like contributing members of society. They must have dignity. They must be afforded the opportunity to do something constructive. They must be able to interact socially with their peers. They must be more fully integrated into greater society.

Esther, PARENT

The province should embrace a culture of inclusivity; through funding a program overseen by a multi-disciplinary team of mental health professionals and parents with lived experiences – while enhancing the resiliency and coping of parents.

Christine, PARENT



Young People with Autism and their Families Face Long Wait Lists

In Ontario, more children with autism are on a wait-list than are actually receiving government-funded intensive behavioural intervention (IBI), a resource considered crucial in the early development of a child who has been diagnosed with autism. As of March 31, 2015, for children the wait time for the Direct Service Option to receive IBI services was 27 months, and 29 months for the Direct Funding Option. At the same date, the average wait time to receive Applied Behaviour Analysis (ABA)-based services and supports was 13 months.¹

One family who shared their experience with IHSTS reported spending tens of thousands of dollars on private treatments and was on the verge of selling their home before they were finally approved to receive the government-funded treatment. Yet this family categorized themselves as “one of the lucky ones” that actually had access to funded treatment at certain points in their child’s life.

Some families who wrote to us have struggled with the system for years to find support for their children with FASD. Even when the young person was acting out violently, they were told they would have to wait a long time to obtain the treatment the young person needed. Even when families were in crisis we heard of 30-day waits for treatment—sometimes longer. We heard that hospitals are often the worst place to go in a crisis especially for children with behavioural needs because they often turn the young people and their families away. In other cases, there was no place for the family to take their child to obtain assistance. Tragically, some of these children end up being “dropped off” at the doorstep of government run facilities or funded agencies when parents run out of all other options to obtain care for their child. Some parents told us that their child languished for months—or years—in hospital beds because there was simply nowhere else for them to go.

1. Source: <http://www.auditor.on.ca/en/content/annualreports/arreports/en15/4.01en15.pdf> pg. 584.



"We need equal support no matter where we live."

Young people want support provided close to home in or near their own communities. Unfortunately, access to even the most basic level of care is not available to young people in many parts of Ontario. When they are placed in care settings far from home they lose regular contact with their support systems. Regular contact with their family members can become difficult due to the high costs of travel, parents not being able to take time away from paid employment or the demands of caring for other children or elderly family members. This is especially true for young people living in northern remote and fly-in communities. This separation is not only agony for both parent and child, it is also unnecessary and inhumane.

It was evident in the submissions that access to services and supports varies widely in Ontario and depends on where a child and family live. For example, children and families in rural, isolated, northern and Aboriginal communities do not have access to the same level of service available in urban or southern communities. Thoroughly trained staff must be available to the families who need them, regardless of their geographic location. At its heart this is a matter of equality and equity. In their submissions young people and their families living in the north asked for access to the same level of supports and services available to other youth and their families in the south. They simply want to be treated the same.

Children and youth with mental health needs are not bad kids; nor are their parents bad parents. The key to early intervention and support is integrated and coordinated delivery of services, and flexible, inclusive, respectful and multifaceted responses.

Sheryl, PARENT

"We feel like we are subsidizing Ontario's support systems out of our own pockets."

Young people and families made repeated mention in submissions about the overwhelming criteria and lack of information about available funding supports and resources. It is apparent from reading stories about their experiences trying to obtain financial assistance that the issue of funding needs its own focus in order to explain the barriers and issues and bring to light the hurdles and struggles children and families face as they attempt to access funding.

Left without support to navigate through the complex web of funding sources can place enormous financial and emotional stress on the very families they are intended to help. When parents discover their child has special needs, they are typically launched into a maze of government agencies and support systems. All of a sudden their lives become entangled in a seemingly endless list of acronyms tied to resources such as SSAH (Special Services at Home), ODSP (Ontario Disability Support Program), ACSD (Assistance for Children with Severe Disabilities), IBI (Intensive Behavioural Intervention) or CCAC's (Community Care Access Centres)—to name just a few

Parents who made submissions told us repeatedly that the rules governing what is covered and what is not covered can be confusing and unfair. For example, when funding is attached to parental income, no allowance is made for what a parent has to spend to provide care for their child. A family could be denied financial or other forms of assistance if their combined income is \$75,000, despite the fact that they might spend \$30,000 per year on uninsured care for their child; meanwhile, a family making \$45,000 would be given all the resources they need: same net income—different level of support.

I had a lot of dental work because of my disability. At one point I got 11 teeth pulled out and it wasn't covered and my parents had to complain to get the funding. It should be covered.

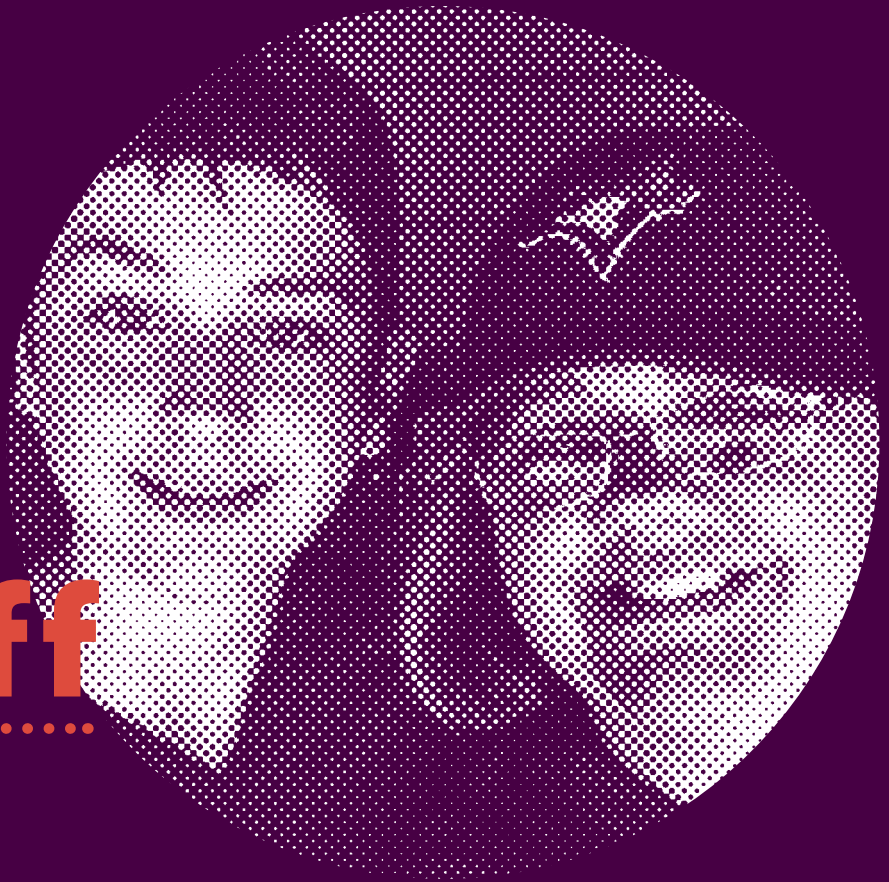
Rana, YOUTH ADVISORY

I believe all income supports should be delivered like a pension, and the expenses should be appropriately accounted for on annual income tax forms we all submit.

Dawn, PARENT

MY STORY

cliff



"We got him on a wait list as soon as we got the diagnosis [of autism] for government funded intensive behavioural therapy. But we were told at the outset that the wait time would be two and a half to four years. So just like any other parent in this situation, we paid privately to start [treatment] right away. When you're told, 'this is what your kid needs and right now is the critical time to start this therapy.' You do whatever it takes, so we cashed in our savings and a bunch of our assets, and applied to a bunch of charities to privately fund applied behavior analysis therapy as much as we could. We were pretty broke by the end of it. I think we spent between \$50,000 to \$70,000 on private therapy and we were literally on the verge of selling our house. When we were in the process of listing our house we got the call that Cliff's number had come up and that we would start receiving government funded intensive behavioural therapy. We held onto the house with our fingernails."

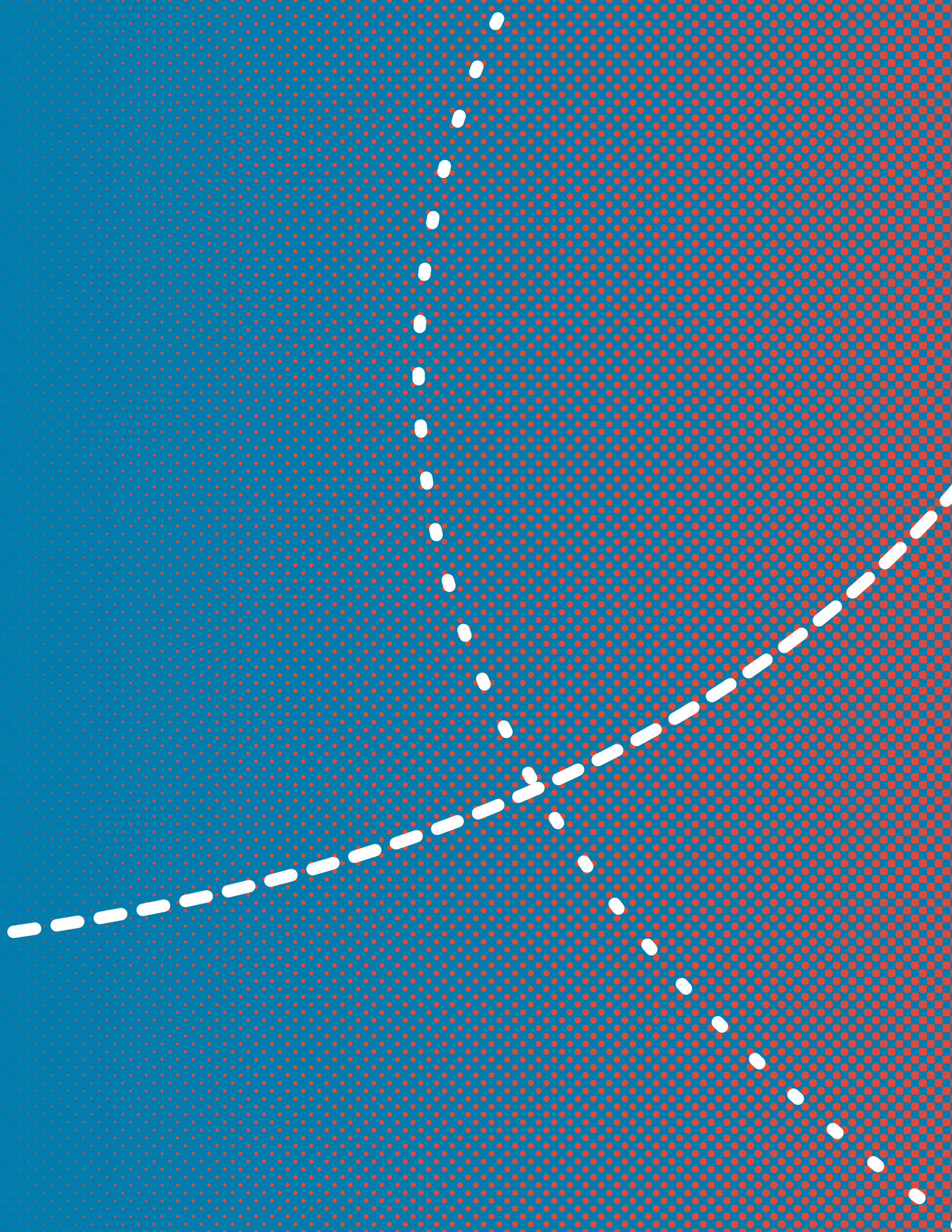
– Laura, MOTHER TO CLIFF

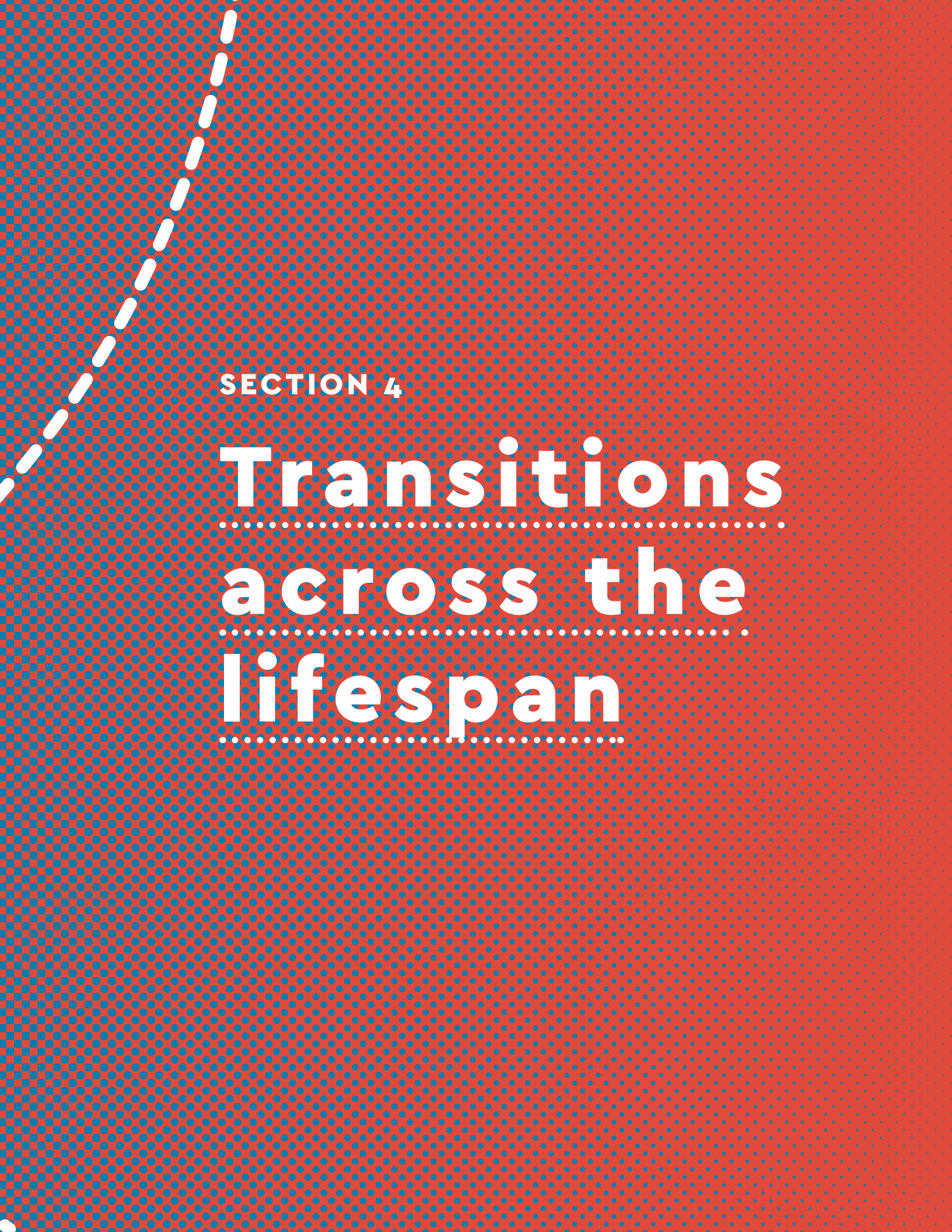
RECOMMENDATIONS

SUPPORTS AND SERVICES

- 1.** All government of Ontario ministries providing supports and services to children and youth should establish a youth advisory table and work in partnership with this table to review policies, programs and new service initiatives that impact the lives of young people with special needs and their families. Ideally this should be an inter-ministerial youth advisory table.
- 2.** The government of Ontario must ensure equitable distribution and access to support services for children and youth with special needs across the province.
- 3.** Children and youth with special needs must be placed at the centre of all decision making affecting their lives and when receiving supports and services.
- 4.** Government must eliminate waitlists for supports and services for children and youth with special needs. Information on the progress towards meeting this goal must be made public and widely disseminated.
- 5.** Government ministries responsible for providing or funding services for young people with special needs must provide an easy to access and transparent accountability process for filing complaints. Children, youth or families making a complaint must receive a real response to their enquiries or complaints within a specific window of time, e.g., 10-14 business days at the latest.

- 6.** The government of Ontario, in conjunction with a youth advisory, must create an on-line “one-stop-shop” resource for young people with special needs (and their families). This resource should inform them of their rights and all available resources designed to meet their needs.
- 7.** All government ministries with a mandate to serve children and youth with special needs must provide wrap-around supports for these young people at every stage of their growth and development.
- 8.** As part of licensing and funding agreements, governments must ensure that staff of support and service agencies working with children and youth with special needs receive on-going training, professional development and salary compensation they need in order to provide the best level of care to Ontario’s children.
- 9.** The government of Ontario must continue to support and expand the availability of peer mentor models or “buddy systems” where youth with special needs are supported, trained and supervised to assist other youth.
- 10.** The government of Ontario must ensure all children and youth receive proper and timely diagnosis and early intervention. Information on the progress towards meeting this goal must be shared with the public.





SECTION 4

Transitions across the lifespan



TRANSITIONS ACROSS THE LIFESPAN

Transitions are significant moments in the lives of children and youth. They mark points in time, stages of life or simple shifts in the course of a day. Young people told us that how transitions are handled can have a deep and lasting impact on both their daily lives and futures. In their lifetime young people move through different phases of growing, learning, attending school, reaching adulthood and becoming independent. They need the support and encouragement of their families and communities to make these transitions as smoothly and as positively an experience as possible.

This support and encouragement is equally important for children and youth with special needs whose transitions can be times marked by great uncertainty and worry. Handled well, they can also be times of great opportunity and growth. Sadly, children and youth with special needs report that they often are not supported at these transition points in life because the resources they and their families need are unavailable or inadequate. In many cases, even simple transitions during a school day, from home to school or classroom to classroom can become overwhelming or impossible because our social and institutional systems of support, quite simply, are not built “for them”. As a result, their needs often go unnoticed and unmet.

The transition from hospital to home — “Our families need more help.”

We heard numerous stories about children born with special needs who spent a great deal of time in hospital in their first days, weeks and even months of life surrounded by 24-hour professional care, expensive medical equipment and every support required to keep them healthy and enable them to gain strength. When it came time for them to be discharged the process of transitioning out of hospital to home was often difficult, and in some cases dangerous, because they did not have all the necessary medical equipment or other supports at home that they needed. Some children required 24-hour care that the family could not afford or provide. The problem, according to parents who shared their stories with us, is that they were left on their own to try and figure out how to provide the same level of care for their child once they were settled at home.

This transition from hospital to home can bring sudden and unanticipated change to the lives of young people, their siblings and parents. Families shared with us that they suddenly realized that they lacked the skills and training to provide all the care their child needed. This was especially true for families who lived great distances from medical facilities and expert care. Many families reported feeling a sense of abandonment and isolation that took a substantial physical, emotional and mental toll on them. Even for families who lived in urban areas but lacked access to convenient transit, something as simple as taking a child to an appointment was difficult, financially challenging or even impossible.

Life transitions should be intentional, well-timed and tuned to the current needs of the individual.

Ingrid, PARENT

Because I have Asperger's, sometimes it's hard for me to make friends. Due to extreme bullying that happened to me in elementary school, I have trust problems and so I usually assume that I'm not included.

Ariel, YOUTH

The day I took him home from hospital was a great day but also very scary. We'd had so much support at Sick Kids and now suddenly we were all alone with a still very sick and complicated baby. We got no sleep for the first three days and only one nurse who dropped by for 15 minutes to check his heart rate. He was still sick and on so many meds, and his g-tube feeds, and wound care. We had to be up every 30 minutes at night and provide constant care during the day. Why did they send us home so unprepared and without proper support?

Anonymous, PARENT



The transition from home to school — “We feel isolated and overwhelmed.”

Moving from a highly supportive, familiar home or day treatment environment into the general population of a school system can be a traumatizing experience for children and youth who were used to individual attention at home or in a special care setting. When schools fail to do an effective job preparing supportive classroom environments where differences are openly acknowledged and welcomed, children with special needs experience staring, cruel teasing, stereotyping and bullying for the first time.

Some young people told us they needed to be introduced to school gradually with a curriculum matched to their abilities so that their physical and emotional resources or ability to focus and concentrate were not overwhelmed. The transition from home to school must be planned with care or it can set the young person up for failure. The need for these gradual transitions doesn't stop at age 18 either, and young people going on to college and university told us they too require a period of adjustment to the stimulation and intensity of a crowded and noisy new learning environment.

The problem of bullying

Many young people who made submissions to IHSTS told us how crushing it was to enter school and face bullying from their peers when previously they had enjoyed a kind circle of friends and family. Such transitions can be difficult for any child. But for children with special needs, who often get singled out by peers, transitioning into school for the first time (or to a new school) can mean the end of feelings of security and happiness outside the home.

One youth told us that the extreme bullying she experienced in elementary school continues to limit her ability to connect with other young people as an adolescent. She is highly reluctant to approach new people for fear of being rejected. For some young people, being on the receiving end of this kind of treatment makes them want to just stay home when they are not in school rather than reach out into the community and have the normal socializing experiences that other people their age take for granted.

Bullying can take on a less noticeable form when it comes from adults. We heard from a mother whose children with autism attended a school where they were expected to function as though they did not have special needs. They had to remember to report to the office for medication and collect and catch up on homework when they had been absent, among other tasks. This was impossible given their particular needs. Yet support for them in the school environment was absent. Another parent told us of a practice called “time on the wall” where their child with autism was placed against a wall in the playground when he was perceived as having misbehaved. The child found the punishment degrading and terrifying.

Families were clear that their children needed support in the transition from home to school. Educators often don’t understand that it can be difficult for some young people to adapt to being in a sometimes large and confusing social and institutional environment. Teachers and peers may not understand that young people with special needs have unique requirements and ways of relating to others socially. They felt that providing more awareness within schools about how the classroom poses challenges for students with special needs would be a helpful first step toward creating a safer, more welcoming learning environment.

There is an attitude in government that parents are the best caregivers. While true, it is not always the case, and parents and caregivers become exhausted too. There needs to be funding for more respite care. Parents should be able to use that money in the way they see fit to obtain respite.

Christine, PARENT

Transition in school for me was a big, huge stress. Our kids they don't get the professional support.

Anonymous, PARENT

The areas of highest need in our experience are within the school system (which was frankly a nightmare).

Nancy, PARENT

It's something that should just be a natural flow from one school to another. Parents shouldn't have to fight to get their kids recognized as people, just because they can't speak or they can't move on their own.

Marcy, PARENT

I believe the continuum of support seems to break down at the entry to high school. Many children also seem to flounder as they enter the daunting stage of preparation for post-secondary education. These young adults struggle to find meaningful engagement in their schools and inclusive, supportive social communities that do not marginalize them or take advantage of their vulnerability.

Wafa, PARENT

"It's a challenge moving from classroom to classroom and from school to school"

We were informed that moving about inside a school can be a major challenge for children who have significant mobility issues or who are medically fragile. Because these young people often rely on portable medical equipment and wheelchairs to get around they may not be able to travel great distances between classrooms or move from floor to floor in a two-story building if there are no elevators. Other children who experience difficulties with daily school transitions are those who have mental health needs or autism. Some of these young people require significant one on one support. Many receive it in the early years of learning but, as they get older, they may lose support due to funding cutbacks or lack of availability in some school jurisdictions. Young people and parents told us that these supports are necessary and must continue throughout a child's entire journey in the school system.

Accommodation can be a major issue. One family told us of their difficulty finding a middle school willing to accommodate their child's complex care needs. Their child's elementary school integrated him fully into the classroom but he lost his support system in middle school where the attitude was one of segregation. Children with special needs in this middle school were not permitted to go outside during playtime and so he would end up sitting separately from his classmates during lunch. The family considered this an outrage and deeply disrespectful to their socially engaged child.

Other parents reported that they had to renegotiate accommodation rules with each new educational institution that their child attended. Middle school was a particular challenge for many children with special needs. We heard from families who told us that even within the same school, in one grade a student would be well supported and then, without warning, once the student graduated to the next grade support would be unavailable. Some students required near-constant supervision to ensure that they understood what was being taught and that they were keeping up with their work. When support is withdrawn, the families say, these students are set up to fail.

Transitions can be particularly difficult for students with autism. Some parents who made submissions said that when transitions are



What we need is a bigger amount of Asperger's classes in schools, mainly elementary... Two or three teachers per class with one class in each school... Simply being in a small class with extra attention given and being eased slowly into full integration would be good enough to help these kids.

Hannah, YOUTH

not done well, their children can become depressed and even suicidal. Some schools have asked parents of children with autism to choose between regular classes with no accommodations or special education classes designed for youth who are developmentally delayed. However, many individuals on the autism spectrum have no global delays but do have challenges that require accommodation. Parents of these children are sometimes presented with a difficult choice: integrate their children into a regular classroom without accommodations, or place their children into an inappropriate classroom designed for children with developmental delays. This is an unfair practice that in no way accommodates the need of the child.

One youth who made a submission presented an interesting idea for accommodating children diagnosed with Asperger's Syndrome. He suggested that each school establish a dedicated classroom for children that need extra teaching support. This way, students get extra attention while they become accustomed to routines and expectations. Lunch would also take place in this classroom, as students can find the lunchroom noisy and overwhelming. The dedicated classroom would protect these vulnerable students from situations in which they experience overstimulation and extreme anxiety.

We need help creating appropriate programs for children with autism in secondary school. My son is heading to high school with no skills and no academic foundation to be successful. How can a school be allowed not to provide for my son's needs?

Susan, PARENT

The transition to high school was tough. My son does better when he works one-on-one with people, especially if it always the same person. He seems to handle it better. Otherwise he gets too stressed. When you have a child with different abilities, especially in high school, and you have to meet four or five different teachers to try and explain stuff to them. They have no time to read the files ahead of time, is what I was told. So it was like, 'then you can't help him'. They need to make more time to get to know their students, or they need to change the education system to something different.

Debbie, PARENT



"The transition from elementary to high school is difficult for us"

Many young people told us they found the transition from elementary to high school especially difficult, as one-on-one supports often disappeared, leaving them particularly vulnerable and often fearful. High schools were far larger than elementary schools and social interactions more complicated and difficult to initiate, putting students with special needs at greater risk for being isolated and marginalized.

Some young people told us that high schools were less welcoming and more stigmatizing than elementary schools. They told us that high school teachers are busy and ill-prepared for teaching students with special needs. Many young people reported that they had to explain their unique situation multiple times to multiple teachers who may not have examined their files beforehand. They were struck by the lack of coordination and unpreparedness among school staff. This reality can be challenging for even the most outgoing student. And for students who may have difficulty communicating, the situation can border on the unmanageable.

Nicole



"I love school. I was always a very social kid. I made lots of friends, and kids would fight over who would get to push me around the school. Stuff like that. It was good. Elementary school was a good time. High school, grade 9 was a bit difficult. I was the only student they had who had a disability and was in mainstream classes. I was in all academic level courses. I think some of the teachers had never really interacted with a student with special needs before. I remember the first teacher on the first day of grade 9 said 'What are you doing in my class?' I remember the biggest thing was, our high school has 2 floors, and they had never thought about a fire safety plan. I asked about it, and they told me I would need to wait until the

fire department came and got me. I was thinking, 'I'm not OK with that.' They tried telling me it was too much of a liability for school staff to help me down, but me dying in a fire, I guess that was ok to them".

Nicole's ideas on how to combat this problem: "Education for teachers, and students, about being different, and what it means to be different. I think some people think you just need to tolerate diversity, but I think there is a difference between tolerating, and embracing something. So they can learn more about how to embrace."

For too many years, youth have lost their lives, their educational potential and their earning potential because we have had an 'out of sight, out of mind' mentality. We have ignored the needs of so many for too long. It is time that we practice what we preach: to support youth with the necessary accommodations.

Sheryl, PARENT

"Moving from high school to post-secondary education can be exceptionally difficult."

For a student with special needs, choosing a post-secondary institution involves much more than just picking a favourite school. We were told that a college or university-bound student has to invest an extraordinary amount of time researching which schools can best accommodate their needs – indeed, whether any school can accommodate them adequately. Young people expressed frustration at having to invest so much time discovering what supports are available, whether attendant care is available, what it will cost, where they will be able to live, where to access assistive equipment and much more.

For young people finding accommodations at post-secondary institutions was difficult because there was never any certainty that the accommodations would be provided in a timely way or at all. For example, assistive technologies available to a student in high school

My son is still without accommodations and it has had a hugely negative impact on his well-being, his achievement and his ability to participate fully in the life of the university alongside other students.

Joanne, PARENT



are not guaranteed to be available for them at a college or university. In other words the equipment they depend on to learn doesn't stay with them as they progress in their education. They don't get to keep their equipment. One parent shared a story about her child being caught in a struggle between government ministries over who would provide her child's adaptive learning equipment. While the struggle went on her son was deprived of his education and made his transition to post-secondary education virtually impossible.

Young people also told us that some colleges and universities viewed the provision of supports and services to students with special needs as an afterthought. Even when accommodation was available, information about how to obtain it was difficult to find. Young people also told us that the fact a student is forced to choose a college or university based on their support services is ludicrous and a shameful example of inequality.

The transition from school to work — "We just want a fair chance to work."

The statistics on employment in Canada show the difficulty people with special needs face trying to transition from school to work. Hidden in the numbers are unknown stories about the lack of accessibility in workplaces to outright discrimination in hiring practices. In submissions made to the IHSTS project we heard repeatedly that young people with special needs lacked the opportunities other youth enjoy and struggled to find employment that matched their abilities and capacity to work.

Difficulties finding or keeping employment begins in adolescence for youth with special needs, when many other young people are obtaining their first summer jobs or other valuable work experiences. We were told repeatedly that young people with special needs are unable to find any type of employment.

Transportation to work is another major concern. If a support worker is not available, a young person with special needs is often unable to access whatever employment programs or jobs that do exist because they cannot travel to these sites independently. Parents, many of whom are struggling to make ends meet and use public transportation to get to their own jobs, are not able to provide transportation

Unlike other students I had to worry about more things than academics and social life. I had to ask each university about the resources they provided for students with disabilities.

Hibaq, YOUTH ADVISOR

Employment barriers

47%

47% of people aged 15–64 with disabilities in Canada are unemployed compared to seven percent for Canadians who did not have disabilities.¹ Among Canadians aged 15 to 64 with disabilities who were not in the labour force, 18 percent stated that their condition completely prevented them from working. Among young adults with disabilities (aged 25 to 34) with a severe or very severe disability, 33 percent reported having been refused a job in the previous five years as a result of their disability.²

Persons with disabilities are more likely to be employed in specific occupations such as personal service, customer information service occupations or sales occupations.³ This, in part, reflects lower education attainment, as only 16 percent of persons with disabilities aged 25 to 64 have a university degree compared to 31 percent among persons without a disability.

1 Source: <http://www5.statcan.gc.ca/cansim/a26?lang=eng&id=1150005>

2 Source: <http://www.statcan.gc.ca/pub/75-006-x/2014001/article/14115-eng.htm>

3 Source: <http://www.statcan.gc.ca/pub/75-006-x/2014001/article/14115-eng.htm>

After I completed my Masters degree in England I came back and thought I would walk into a job. I had a Masters of Law from a global top 40 university!

But I didn't. First four months, then six months. I couldn't even get an interview. Oh, I could talk for hours on special needs and employment. People with special needs are hugely untapped.

The unemployment rate for people with special needs is now higher than the general population during the great depression!

You're looking at 35% unemployment. That's huge! You start wondering. 'Why can I never get a job?', 'What is wrong with me?' Professionally, you have a giant hole in your resume that keeps getting bigger. It's incredibly frustrating.

Tim, YOUTH ADVISOR



for their child. The problems become even worse at graduation or age 21 for students unable to graduate. It is a major barrier because there is little support for parents and families to help provide work opportunities to their adolescent children or young adult children with special needs.

One family told us that after having completed a co-op placement with a major corporation, their young adult was told he was going to be hired full-time and completed all the related paper work with the human resource department of the company. Despite repeated attempts to get the company to honour its promise, the young person was never actually hired. The youth has now completed high school and has

no prospects for another co-op placement or to obtain further work experience to help increase his chances of finding full time employment.

This story highlights the fact that it is not only students with special needs and their families who need assistance to support the transition of young people into the workforce. Employers also need awareness and information that will give them confidence in the skills and abilities of workers who have special needs. Young people told us that placing a resource person in the workplace for a young worker with special needs may be the best possible way forward. A resource person could help employers learn more about how to create supportive work environments that provide opportunities for young people to excel and realize their gifts, skills and potential on the job.

At present, we as a society rely solely on the goodwill of employers to hire young people with special needs. After hearing young people's stories, we as an Office feel there could be better links between employers and the education system so that there are pathways for students with special needs to transition from school into supportive work environments. This is more than just an employment or education issue; it is an equity issue and a community health and community development issue for the province.

"Our needs don't just magically disappear at age 18 so why do our supports?"

We heard that when young people "age out" of the support system for children and youth with special needs, families face huge caregiving challenges. The families that made submissions to IHSTS spoke of feeling anxious and fearful as their child approached their 18th birthday. This is because young adults with special needs lose many resources to which they were entitled as children. They often lose access to counseling, nursing, occupational therapy, speech therapy, mental health supports, some medical resources and other necessities.

A major problem that families reported was the loss of funded care during the day. Parents living with adult children who require 24-hour support are provided with few options – typically, they either have to quit their jobs and lose valuable income or pay the very high costs of adult day services that are not funded in Ontario. Parents

Hiring disabled people should be a positive thing. They need to see that we can add to their success.

Patrick, YOUTH ADVISOR

There needs to be a transition plan and assistance beyond high school.

Emma, YOUTH

At the age of 18, the family is hit with a speeding truck. After being very well served for 18 years (by the health care and school systems), our children are unceremoniously ejected from funded care. They are thrown into a system that has no regard for the fact that they cannot work, they cannot volunteer, they cannot function without assistance.

Esther, PARENT

I write because in the children's world we work hard to establish connections and relationships with these fragile children and due to the diagnosis this can in fact take years. These children love contact and form meaningful relationships that enable them to grow. We then put them in adult care with no contact, no feelings and no care. Please ask the adult world to burst its bubble and get engaged, get connected and form relationships for the future.

Glen, SERVICE PROVIDER

also expressed a yearning to see their children contribute meaningfully to society and interact with their peers as they did before they reached adulthood. But often, the only way to accomplish this is through adult day services.

We also heard from professionals concerned about specific challenges that young adults with special needs face. For example, a young adult with autism will be transitioned out of a school or youth group home once they come of age even if their intellectual functioning is at the level of a four or five year old. Professionals are asking that these young people be treated on an individual basis rather than be subject to blanket policies about aging out of the system. Some people with special needs require a high level of support throughout their lives. Professionals, families and caregivers wondered why there was no mechanism to keep young adults in living situations in which they feel happy and secure regardless of their age.

Parents told us that service agencies sometimes present adult children diagnosed as having autism in their care with choices they are not capable of making, such as decisions about moving toward independent living. This can set up young people for failure and leave families desperate and caught in an endless struggle to find supports to make up the difference in the level of care their adult child with autism was receiving as an adolescent.

We heard from parents of young people with fetal alcohol spectrum disorder (FASD) who said the transition out of school and into adult life was particularly difficult. FASD is a permanent brain injury that

At the age of 17 I was told I had to change hospitals, I was no longer considered a child, and I had to go to an adult hospital. There are way too many gaps in this transition.

Silvia, YOUTH ADVISOR

I know that a woman, her son went here, she's having a concert in a couple of weeks to raise money for post-18 programs. So that responsibility now is going on the heads of parents to arrange care for their adult child.

Anonymous, PARENT



Employers need to be exemplars in the workplace. They need to be supportive to the employee.

Patrick, YOUTH ADVISOR

When they hit 18, there's no group homes, there's no programs and it's really sad when you see one of these young people just shuffling – you know, just walking the streets, because they've lost everything.

Anonymous, SERVICE PROVIDER

I am working hard to make this work. People don't know how hard my life is. But I want to be out there in the world. I have overcome so much. I am doing well. Half the problem is done. But I am still here.

Cliff, YOUTH ADVISOR



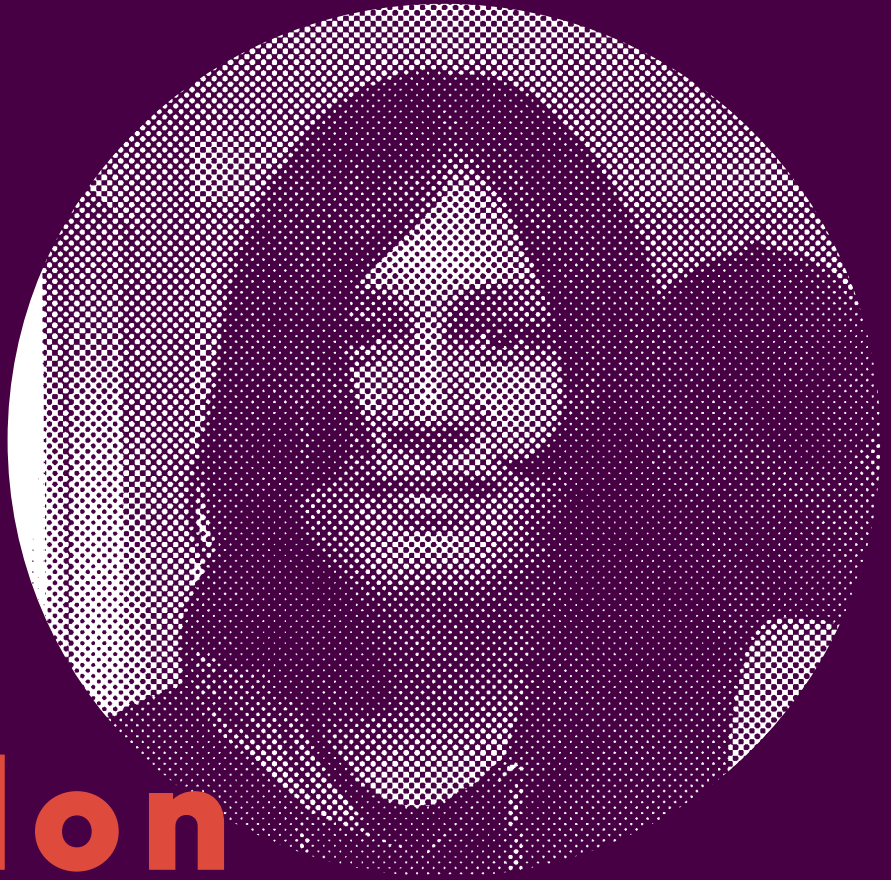
can cause a range of learning challenges, behavior issues, and can mean the person has difficulty learning from mistakes. This means that many, if not most, young people with FASD will never have a full-time job and cannot live independently. Once publicly funded schooling has ended, families often find themselves in dire need of support including respite care as well as help finding suitable housing to support independent living for their adult children.

In high school I had great support systems – applied behavioural analysis therapist, one-on-one teachers, and educational assistants – until I hit 18 years old – but going into transitioning into an adult you have nothing. An accessibility person is available in college, but nothing else. You're just dropped.

Aly, YOUTH ADVISOR

The ministry should look at keeping young adults in school until they are 25 years old. Too many children when turning 18 years or 21 years but who function as two to five year olds have nowhere to go. Just because they turn 18 or 21, why should they not stay and continue to be challenged and cared for by people who know them best?

Glen, SERVICE PROVIDER



Brandon

Brandon: "I am 19 years old and not going to high school anymore. I have a learning disability, partial FASD and ADHD. I need to have things explained to me different ways. Now that I am not going to school most of the time I just stay at home. I'm trying to figure things out, I guess. Staying here mostly. I'm not really sure what to do."

Mom [Debbie]: "We are working on getting him on disability assistance. Then we're working on getting him his own place, maybe. We're going to be applying for a worker to come in to see him and work with him. It's just that the waiting list, and the time for the applications are a pain. The applications are hard to fill out and the waiting lists are long."

Brandon: "It's hard for my mom to help me with all these things. I wish there was someone who was around that could help me figure out all these things. That would probably help out a lot. It helps me when I can work with the same person. They get to know me and I get to know them."



Development Services Ontario requires that assessments are done to determine what funding and services the youth needs from a transition to adult system. Parents indicated the frustration of having to re-do assessments of well-established, long standing needs. Also wait list applications for funding that transitions youth to adult systems must ideally be done by 16 years of age to avoid a funding gap. Youth and families could be waiting for two or more years for services.

Anonymous, PARENT



Novelette

Novelette lives with epidermolysis bullosa. She was receiving many services until she turned 18 years old. "When I turned 18, everybody just dropped me. All my supports in the specialty fields that I was seeing at Sick Kids Hospital — Gastroenterology, Hematology, Dermatology, and the dentist — were gone. Nobody said, 'OK this is where you can go next'. I was just left in the lurch.

It's all well and good for there to be these great supports to help kids stay alive until we're 18. But then, after that, you still need to keep that support going to ensure we're going to happy, healthy functioning adults. They can't just drop off and leave us to just wither away without the right care. Once you lose the right care, it's easy for something to happen, something that falls under the radar, but by then it might be too late. If I wasn't as healthy as I am and able to do the things I want to do, then I wouldn't have accomplished a lot of things, like going to university and getting my degree or learning to drive."

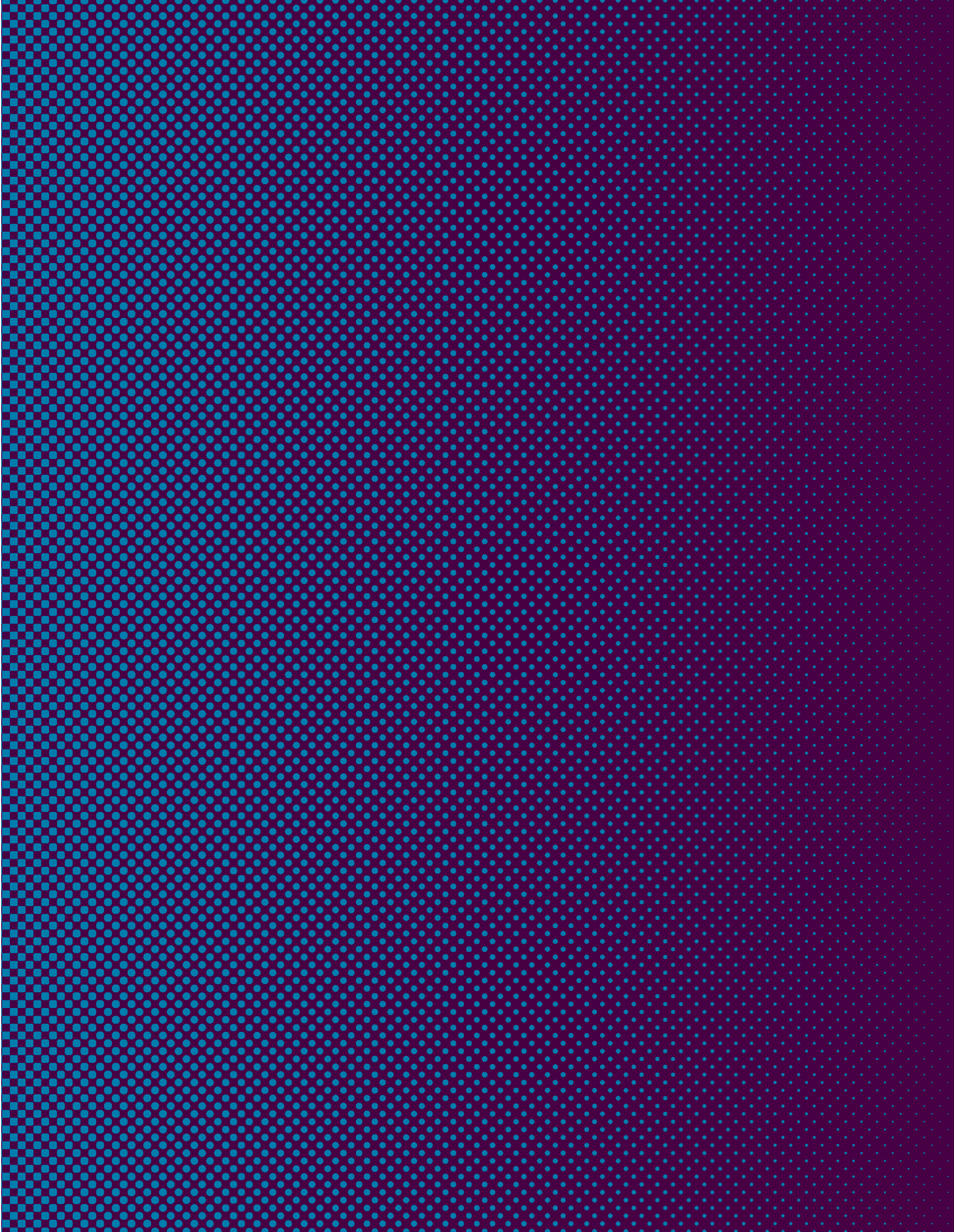
RECOMMENDATIONS

TRANSITIONS ACROSS THE LIFESPAN

- 1.** The Ministry of Health and Long Term care must ensure that the initial major transition in the life of a child with special needs—from hospital to home—is supported and that families have the information, equipment, funding and support they need to continue providing the level of care their child requires.
- 2.** The Ministry of Education must work with their youth advisory table to develop policies and procedures to properly support and assist children and youth with special needs at every point of transition in the school system: from home to school, from class to class, from elementary to secondary and from high school to post-secondary education.
- 3.** The Ministry of Labour must work with their youth advisory to create a matching system for employers and youth with special needs. This system must include employment training, skills assessment and any supports needed for a young person to transition successfully into the labour force.
- 4.** The government of Ontario must work with a youth advisory table to develop strategies and incentives to support the hiring of more young people with special needs.
- 5.** The Ontario government must work inter-ministerially to supply assistive devices to young people who require them to participate in the workforce.

- 6.** The Ministry of Colleges Training and Universities must work with their youth advisory table to develop in-service training and awareness programs for faculty about how to support the post-secondary student with special needs.
- 7.** The government of Ontario must create continuity of care plans for young people with special needs moving from the child to adult systems so that they do not face gaps in services and supports after they turn 18 years of age.
- 8.** Having a mentor is often the best way to help a young person with special needs move successfully through major transition milestones in life. Provincial and municipal governments must support, expand and raise the profile of sibling and family peer support programs as a way to offer support and guidance during these key times in a child's life.
- 9.** The government of Ontario must recognize and promote the importance of transition workers particularly as a young person moves from home to independence.
- 10.** The government of Ontario, in making decisions about and facilitating transitions, must take into consideration the unique characteristics and capacities of each young person. The young person must be included in this planning process.





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