

Dear Everybody,

**It's time to end stigma for young
Canadians with disabilities**

A REVIEW AND ANALYSIS OF THE IMPACT OF STIGMA ACROSS CANADA

We dedicate this report to all of the children and youth across Canada who have disabilities.

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Executive summary:

Dear Everybody,

It's time to end stigma for young Canadians with disabilities.

In recent years, inclusion and diversity are taking centre stage in the media and in public awareness.

For example, race, sexual identity, mental health, Indigenous Peoples' rights and history, and immigrant and refugee rights have advanced as meaningful social issues and a focus of public attention. That's not to say there isn't still much more work to be done and progress to be achieved on these issues – there certainly is. Nevertheless, the first years of the 21st century have led to many exciting developments when it comes to expanding society's collective understanding of *difference*.

As Canada's largest rehabilitation hospital for children and youth with disabilities, we celebrate the increasing value placed on diversity. And yet, we have to ask, where do children and youth with disabilities fit into the conversation?

How is it that they – or people with disabilities in general – have not yet been welcomed as a part of our society's growing acceptance of difference?* To be sure, there is some evidence that the public is showing more interest in disability issues. When stories about a teenage model with Down syndrome

"It really hurts when people just assume I can't do things, and assume that I'm less of a person than I am. Because I am lovely, for anyone that knows me..."

- Jadine, Holland Bloorview client, age 17
(see page 5 for Jadine's story)

at New York Fashion Week rack up more than a million views on BuzzFeed, Mashable, and social media,¹ that means something. Still, positive examples of visibility such as this for children and youth with disabilities are rare.

Instead, **young people with disabilities routinely face the consequences of stigma – staring, whispers, name-calling, social exclusion, bullying, and outright discrimination – and many of us take little notice.** Many kids, and even young adults, are patronized or overprotected by others. School children are placed for "time outs" in closets² or have their communication devices turned off by those entrusted with their care.³ Those who go to college or university may have

their accommodations questioned or struggle with a myriad of transportation, health, and other challenges. And once they reach adulthood, young people face lower employment prospects on average compared to their peers without disabilities. Those who do not work are often treated as a drain on society, rather than as people contributing their own strengths and uniqueness – like anyone else – to Canada's diversity.

This issue's time has come. It came a long time ago. Children and youth with disabilities face far too many frustrating, heartbreaking, or otherwise damaging barriers – barriers caused, ultimately, by stigma.

* We of course recognize **intersectionality** – the fact that there are many overlapping identities and related systems of discrimination. We believe that all people who struggle against stigma and discrimination are allies together.

People *without* disabilities often possess extensive gaps in their understanding of disability, including the tendency to overestimate the negative impact of a disability and to underestimate how much those *with* disabilities value and enjoy their lives.

In this paper we examine stigma in detail, starting in Section 1

with a discussion about the rights of young Canadians with disabilities, and contrasting this with the realities they experience as a result of societal discrimination and stigma.

In Section 2 we provide a detailed analysis of stigma, including

debunking the negative assumptions about disability that many of us – even people who consider themselves knowledgeable about disability issues – possess, whether consciously or unconsciously. We'll see how people *without* disabilities often possess extensive gaps in their understanding of disability, including the tendency to overestimate the negative impact

of a disability and to underestimate how much those *with* disabilities value and enjoy their lives.

We conclude in Section 3 with a number of recommendations and actions for change for different stakeholders (governments, health professionals, educators, media, parents, friends, and classmates of young people with disabilities, members of the public, and other potential allies), which consist of the changes urgently needed if we are to begin addressing the unacceptable levels of stigma experienced by young Canadians with disabilities.

And we simply must address it. It's wrong. It's unethical. It's a rights issue. **And it's time – way past time – for change.**

Disability and language

Decisions around the use of language to describe disability require thought and consideration from all of us. In this paper, we use person-first language, which identifies the person before their disability (e.g., "person with a disability" rather than "disabled person" or "child with autism" rather than "autistic child," etc.). However, we recognize that not every person with a disability wants to be identified this way or even uses the term "disability" – people self-identify in many different ways. We recommend person-first language when talking about people with disabilities in a general sense.

When referring to a specific person or group, it is best to ask how they self-identify and use that language.

We also recommend avoiding negative language that is hurtful, disrespectful and inappropriate, such as "crippled," "confined to a wheelchair" (as opposed to "uses a wheelchair"), "suffers from ____ condition," and "afflicted with ____." When speaking with and about people with disabilities, avoid language that implies disability is tragic or inherently heroic; always consider the messages implicit in what you say.





"I'm realizing I want to educate people. I want them to think differently, so that's why I speak out now about my disability."

- Jadine, Holland Bloorview client, age 17

The girl who ate lunch alone: Jadine's story

"There's not one day where I don't sit at lunch alone at school because nobody wants to sit with me," says Jadine.

The 17-year-old student is surprisingly calm and matter-of-fact describing the isolating scenario that's been playing out in the first semester of her grade 11 year. Picture a high school cafeteria full of hundreds of kids, eating, talking, and laughing with friends. Then picture Jadine sitting alone in the middle of everything, in a spot reserved for her wheelchair at an otherwise-empty table. Day after day.

"People from my class always wave and say 'hi,' but they never sit with me," she says, adding that at least in the second semester in grade 11 things got a bit better – she reconnected with a friend who had lunch with her some days, so it was not quite every day that she was sitting alone.

Jadine is no stranger to stigmatizing situations; she faces them multiple times a day. "The biggest thing is, when people look at me with that look of, 'Oh, poor you, your life must be so hard!'" she says. "I understand that my life is a bit harder than everyone else's,

but it makes me much stronger having to adapt. I have flaws like we all do. Just mine are more visible than most."

She also puts up with stares, looks of disgust, and hearing people talk about her behind her back. Sometimes people assume she can't understand them when she can, and talk to her as if she is five rather than 17. "When people see me, they just see the chair and don't realize that I actually have a brain and can say things and have feelings," she says.

So here's a dose of reality: Jadine is intelligent. *Really* intelligent, and articulate. She has wisdom far beyond her years, and a serenity and comfort level about her life that most of us would envy. She comes from a happy family with four siblings, her mom, and a large extended family. She loves swimming, is a voracious reader, and has her sights set on becoming a bestselling author one day. She wants to use her writing to become an advocate for "youth who are different and wonderfully made" (that is, youth with disabilities).

"I picture my life at thirty to be the most amazing life that anyone could ever live," she says, with considerable conviction.

And yes, Jadine also has a disability. Cerebral palsy to be exact, which affects her speech, her legs, and her upper body strength. She was born premature, 2 lbs., 13 ounces. A real survivor.

Jadine has been an inpatient at Holland Bloorview a number of times following surgery. "It becomes like your second home, because you never have to wonder if you're going to be accepted there."

So does stigma just roll off her now, given that she experiences it daily? "Believe me, it doesn't roll off me. But I'm saying it doesn't hurt as much when you expect it. It doesn't ever stop my day like it used to, or have me crying myself to sleep like I used to."

"Now it just makes me have a backbone, so I'm actually thankful. When people stare at me, I just smile and wave. And when people ask me questions, I answer, because I prefer they do that instead of making assumptions or talking to other people about me behind my back."

"I'm realizing I want to educate people," she says. "I want them to think differently, so that's why I speak out now about my disability." ☠

"People should know how to treat other people properly, no matter what place they come from, what disability they have, and what skin colour they have."

- Jillian, Holland Bloorview client, age 8



Section 1:

Childhood disability in Canada

In Canada, there are at least **400,000 children and youth** (ages 0 to 24) **with disabilities**⁵ – a considerable population, equivalent to the size of some of Canada's larger cities (such as London, Ontario, or Halifax, Nova Scotia⁶). However, given that many disabilities go unreported or undetected in childhood, the number is likely much higher.

But this number tells only a fraction of the story. What outcomes can young Canadians with disabilities expect? Are they on a level playing field with other children? Does Canada support them and give them the opportunity to contribute their full potential – or not?

Rights

A child with a disability in Canada – just like any other child – has rights, as outlined by the **UN Convention on the Rights of the Child**⁷ (CRC). The CRC specifies that children should not be subject to discrimination on the basis of disability, and should "enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community."

The **UN Convention on the Rights of Persons with Disabilities**⁸ (CRPD) provides a more detailed elaboration of these rights in many areas, such as independent living, rehabilitation, and personal mobility. The CRPD guarantees the right to "reasonable accommodation" in the workplace, and guarantees children the right to an inclusive education.

Turning to Canada, a child with a disability is guaranteed a variety of rights under the **Charter of Rights and Freedoms**,⁹ including "life, liberty, and security of the person" and an equality guarantee granting "equal protection and equal benefit of the law without discrimination," including on the basis of disability. The Charter applies to laws enacted by Canada's federal or provincial governments.

The **Canadian Human Rights Act**¹⁰ prohibits discrimination on the basis of disability, and applies to the federal government, Crown corporations, and federally regulated organizations such as chartered banks, airlines, and television and radio stations (each province and territory in Canada also has its own human rights act). Canada's **Employment Equity Act**¹¹ requires federally regulated

employers to take proactive measures to improve employment opportunities for persons with disabilities.

There is no **federal accessibility act** in Canada, as there is in a number of other countries, although the Government of Canada is working on one.^{13,14,15} A national accessibility act is expected to go beyond outlining rights, and require federally regulated organizations to meet specific accessibility standards, while also setting an example for similar provincial and territorial acts yet to be developed.

There currently are accessibility acts in three of Canada's provinces, the **Accessibility for Ontarians with Disabilities Act**,¹⁷ the **Accessibility for Manitobans Act**,¹⁸ and **Nova Scotia's Accessibility Act**.¹⁹ These create mandatory accessibility standards (in areas such as customer service, employment, and transportation, among others) to eliminate barriers for citizens with disabilities. Ontario plans to have its standards fully in force by 2025, while Manitoba has committed to significant progress by 2023 and Nova Scotia just passed its accessibility legislation in April 2017. These acts apply to public, private, and non-profit organizations.

In summary, a child growing up with a disability in Canada today enjoys a broad range of rights, including the right to an inclusive education, the right to employment with reasonable accommodation, the right to social participation, and the right to "a full and decent life."

Realities

Of course having rights and being able to exercise them are two different things.

The reality is ...



25% At least **25%** of children with disabilities under 15 in Canada **have unmet educational needs** (such as a lack of access to the support or accommodations they require)²²



24% **live in poverty**²³ (compared to 15% of children without disabilities under 18²⁴)



53% of children with a disability **have zero or only one close friend**²⁵



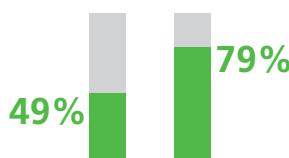
1/3 of people with disabilities in the labour market say they have been **denied a job because of their disability**, and 24% say they have been denied a job interview²⁷



Young people with disabilities are **two to three times more likely to be bullied** than those without disabilities.²⁰ Children and youth with disabilities also report high rates (27-64%) of **being avoided or excluded at school**²¹



Median incomes for Canadians with disabilities are 34% less (almost \$10,000) than the incomes of Canadians without disabilities²⁸



The employment rate of working-age Canadians with disabilities in the labour market is 49%, compared to 79% for Canadians without a disability²⁶

These numbers tell a harsh reality

– while young people with disabilities may enjoy many rights on paper, they aren't afforded the opportunity to have a full and decent life to nearly the same extent as other children in Canada.

"I always find it dispiriting when I see other professionals who sit in a meeting about a kid [with a disability] and say, 'There's not much else I can do.' There is always something else you can do. The growth you see might not always be as large as for some other kids, but it's still growth. You can always help a child to do a little bit more, a little bit more, to increase their independence. And so when I hear a professional who says 'That's it,' I think 'No, that's not it at all!'"

- Primary school teacher

Education

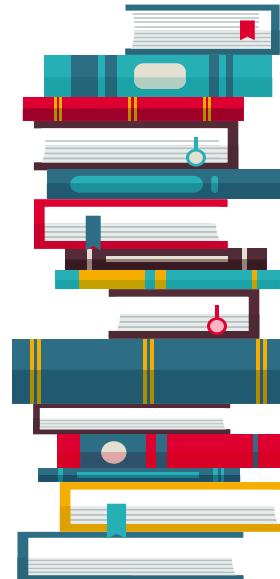
Education is particularly important for children and youth with disabilities, as it can act as a protective factor against societal barriers and discrimination.²⁹ However, for many students with disabilities, getting a high-quality education – one where they feel they belong and have a chance to succeed – can be a challenge.

Across Canada, children with disabilities receive education plans that function as a contract, spelling out the accommodations they are to receive in school. Typically students go through an assessment process, but waiting lists are notoriously lengthy. Once identified, many young people with disabilities do not receive all of their promised accommodations.^{30,31} Funding issues can mean that resources they are supposed to have (like educational assistants or adaptive equipment) are not made available, or not to the extent required.^{32,33} And in fact, each province, territory, and even school board operates differently. According to a report from the Canadian Centre for Policy Alternatives,³⁴ “currently a student with a disability in one part of the country may

receive a considerably different amount of support than a student with the same type of disability in another region.”

Another significant issue is that most classroom teachers receive limited or no training on how to teach students with disabilities.³⁵ Children with disabilities may spend a year with a classroom teacher who has no familiarity with their disability at all, which can lead to lowered expectations, labelling, and other consequences.

For some students with disabilities, attending school in an integrated classroom (a classroom with children who do not have disabilities) involves a significant degree of stigma, social exclusion, and bullying – and for them, school is a daily trauma.^{36,37} A recent investigation in *Today's Parent*³⁸ documents many disturbing cases across Canada, such as instances where children with autism as young as nine have been placed in handcuffs by police, or a case where a grade two teacher led her class in a vote to kick out a classmate with multiple special needs. This was also confirmed in a Holland Bloorview research study³⁹ about social



exclusion and bullying by teachers and students, which documented a number of similarly alarming stories.

Health care

Young people with disabilities and their families navigate a complex and fragmented health-care/rehabilitation ecosystem.⁴⁰ They may receive health services in a wide variety of locations, from an even wider array of professionals. Access to care and outcomes can vary greatly, depending on where they live and the specific providers responsible for their care.^{41,42} The cost to families of raising a child with a disability include many non- or partially reimbursed health care and treatment costs such as speech and occupational therapy, medical equipment and supplies, assessments, counseling, ambulatory services, and more. For many families, these costs can be prohibitive.⁴³

“The staff, for the most part, has been horrific. A lot of teachers...don’t want to know what she thinks. Most teachers turn off the [communication] device for most of the day...The teachers say ‘I don’t need a computer to tell me what to do. I don’t get paid enough to listen to her.’”

- Mother of a 14-year-old girl with cerebral palsy, interviewed for a Holland Bloorview research study⁴⁹ about social exclusion and bullying at school

Young people with disabilities may also face, on a more personal level, barriers in the health-care system caused by stigma. They may not be asked for their input or goals for their own care, or they may be spoken about, rather than included in a conversation, when they are at an appointment. They may encounter health providers with insufficient training, a lack of understanding about their needs and experiences, or low expectations or other misguided attitudes related to disability.⁴⁴

"Having a job means I can be independent and fulfill my dreams on my own terms."

- Sageth, Holland Bloorview employment program participant, age 21



Social inclusion and transitions

Children with disabilities often struggle to make friends.^{45,46} They have lower participation rates in summer camps, volunteer work, recreational activities, and part-time or summer jobs – important experiences for many young people to develop life skills and lead a satisfying life.⁴⁷ Young people with disabilities have a much harder time with transitions – from elementary school to secondary, and from there to community living, volunteer work, post-secondary education, or the workforce. And they can face a lifetime of barriers and painful experiences, from showing up at inaccessible restaurants to receiving pitying looks and intrusive comments.

there are many meaningful and valuable vocations and ways of contributing in life.

However, many young people with disabilities will grow up and enter the workforce, where they inevitably encounter challenges. They may become one of 411,600 “potential workers” with a disability in Canada⁴⁸ – wanting to work, but simply not hired. If they are hired for a job, they might still face exclusion from their peers, denial of job accommodations, a lack of meaningful or challenging roles at work, or trouble advancing.⁴⁹ They might not be treated as someone making a valuable contribution, but as simply the person who allows an employer to check off a box for employment equity.⁵⁰ The onus will often be on them to address

Income and social support

Children with disabilities grow up to face a patchwork of income support streams (all designed in different ways and in different eras),⁵¹ tax credits, and government and community programs – which they and their families have to learn about and navigate. Despite the support available, the cost of raising a child with a disability can be up to three times that of raising a child without a disability⁵² – and this financial burden can be overwhelming for many families.⁵³ When young people with disabilities grow up, they are more likely than other Canadians to live in poverty,⁵⁴ and have, on average, much lower incomes than other Canadian adults.⁵⁵

"My daughter doesn't get invited to any birthday parties. She knows they are happening; other kids talk about them at school, and so she asks me, 'Are we going to so-and-so's party?' And she didn't get an invitation so I don't know what to tell her."

- Parent of a five-year-old Holland Bloorview client with autism

Employment

We must stress that not everyone with a disability wishes to, or is able to, work and those who don't work are no less valuable than those who do. All humans have equal and inherent value, and

serious instances of discrimination – through human rights complaints or the courts. And if they are not able to work, they (and their families) are likely to face stretched community support resources and significant social exclusion.

All of this is not to say that every child with a disability will face all of this at every turn. So many factors play significant roles – such as the degree and type of their disability, parental support, the training and rehabilitation support available, their school and teachers, their family's financial and other resources, and the presence (or absence) of other differences that might marginalize them too.

But make no mistake: every child and youth with a disability faces significant adversity in life, their lives governed by barriers. And behind those barriers are the attitudes of people who placed them there.

Why it all matters

Besides being a significant human rights issue, this issue matters for so many reasons:

- **Disability is an inseparable part of diversity**

Emma Lazarus, a Jewish-American poet of the 19th century wrote “until we are all free, we are none of us free.” We must remember that we can’t have justice, and celebrate diversity, without including people with disabilities. As long as people with disabilities face adversity, inequality, and stigma and are unable to exercise their human rights to the same extent as their peers without disabilities, true societal equality cannot exist. We are in the struggle for full acceptance of difference together.

- **People with disabilities offer unique strengths and talents**

Children and youth with disabilities make our diversity much richer. Students with disabilities for example look at the world in “ways that reveal strength and imagination, challenge the limitations of current teaching, and [reveal] alternate ways of thinking about how students learn.”⁵⁶ The same can be said of the contributions of young people with disabilities in the community, in families, in volunteer work, in the workplace, and in every aspect of life.

We are in the struggle for full acceptance of difference together.

INVISIBLE DISABILITY

A disability that is not visible to others. Learning disabilities, brain injuries, and mental illnesses are some examples. Having an invisible disability may mean that a person experiences less stigma than someone with a more apparent disability. An invisible disability may force someone to disclose their disability (whether they want to or not) to receive accommodations they need.

- **Inclusion makes economic sense**

We are reluctant to make an economic argument for inclusion, to avoid any mistaken inference that human worth relates to the economic value a person creates. Every human has value, period. However, inclusion does make economic sense, and the facts show that taking the needs of customers and employees with disabilities into account provides a great return on investment. Disability touches 53% of consumers,⁵⁷ and the consumer spending power of people with disabilities and their families amounts to \$40 billion annually in Canada.⁵⁸ Companies that are inclusive of employees and customers with disabilities consistently deliver better shareholder value. Inclusion is better for business and for the Canadian economy.⁵⁹

- **Disability affects us all**

One in five Canadians experiences a mental health issue in any given year.⁶⁰ One in 68 children are on the autism spectrum.⁶¹ Nearly one in 10 Canadians report having a disability related to pain.⁶² Most of us know one or more people with a disability, and probably more of the people that we know have a disability than we realize, since many disabilities are invisible. And those of us who are parents never know what the future holds. At any moment, our typically developing child could face a stroke, a concussion, an illness or accident, an unexpected diagnosis, or any number of other circumstances that could result in a disability. This is true for all of us. Disability can be acquired, at any age and by anybody. And many of us will face some kind of disabling condition at some point in our existence. Therefore creating a better society for people with disabilities directly benefits nearly all of us, at some point in our lives, because we too will either live with disability or be close to someone else who does.



"No one should generalize that because a person such as my son can't move or speak and uses a wheelchair and has caregivers.... that it doesn't mean he doesn't want to enjoy his life and be part of something."

- Suzanne, mother of Holland Bloorview client Wesley

The day everything changed: Suzanne and Wesley's story

Let's get the part about "the day that changed everything" over with first: When Suzanne's son was 16, he was playing rugby on a school team one day when he was tackled and his heart stopped. At first no one realized Wesley wasn't breathing, so help only arrived 25 minutes later – by then he had suffered a severe brain injury.

Wesley had been a gregarious, genuine, and kind teenager, Suzanne says, someone "who just amassed friends through his life." But after undergoing lifesaving surgery at an acute care hospital, he was non-verbal and unable to move on his own. And then the real difficulty began, says Suzanne, who describes the next period of her life as "exceptionally horrible."

Doctors told their family to consider end of life planning. Nurses wouldn't let them read medical charts. "They would say things like, 'We don't think you understand this information. Haven't the doctors spoken to you? Do you realize what's happening to your son?'

And then they would tell us all kinds of horrible things about how he might live in future," says Suzanne. The medical care team's approach seemed to place a low value on Wesley's life because of his severe disability. "I would say, shouldn't we be doing physio? And the response was, 'Well, why would we do that?'" says Suzanne. Wesley lost weight rapidly and was getting progressively worse. It felt as if the care team wanted them to give up – instead, Suzanne and her family decided to advocate for Wesley's recovery.

Five months later, Wesley was transferred to Holland Bloorview. It was a major turning point; he started to flourish, gaining weight rapidly. One day a physiotherapist put him on a pedaling machine, and to everyone's delight, he began pedaling on his own (he has his own pedaling machine now, which he uses daily).

Suzanne would take Wesley through Holland Bloorview, and everywhere they went, people stopped to say hello.

"It would often take me 20 minutes to get wherever we were going, because so many people would talk to us," she says. "The fact that he couldn't respond was irrelevant. They acknowledged Wesley as an individual, and a person who deserved to be greeted and spoken with, and it made such a difference. The attitudes of the staff were second to none."

Today Suzanne is very glad she found the strength to advocate for Wesley. "I knew I made the right choice when he started smiling at me again," she says. Seven years after "the day that changed everything," Wesley is now living at home. He's 23 and back to his pre-accident weight of 160 lbs. (he was only 90 when things were at their worst). Suzanne communicates with him using a blinking system and by reading his facial expressions and behavior. "I see so much of him in there," she says, "and I have so much hope for his future."

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Section 2:

Stigma

It hurts. That's the first thing to know about stigma. It *really* hurts, as Jadine says, based on her considerable experience (please see her story page 5).

Stigma, quite simply, is the shame or inferior status that people consciously or unconsciously ascribe to others they perceive as "different." Whether because of our race, sexual orientation, gender or gender identity, level of education, economic status, age, or for any number of other reasons – most of us, at some point, have felt the sting of stigma.

Since the late 1990s, the academic study of disability-related stigma has grown substantially. Today, disability studies scholars increasingly challenge us to view disability as a social issue, rather than a medical issue that needs to be "fixed."

"It's turning disability on its head," says Dr. Barbara Gibson, senior scientist at

Holland Bloorview's research institute, who focuses much of her work on the attitudes of health-care professionals towards disability. "It's saying, we all have different bodies and ways of being in the world, and it's not that some are a problem and others aren't. What's disabling are attitudes and environments that don't allow everyone to function within them."

Once you turn the idea of disability on its head, the world is transformed. A wheelchair is no different from a car, bicycle, or skateboard – it is just another way to get around. An education system that expects every student to learn the same way looks short sighted, because different learning styles work better for different people. The world is full of "a wide range of different human abilities that manifest differently in different people," says Dr. Gibson, who calls this **diversability**.

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She is grateful to live at a time where medical science has discovered neuroplasticity, the brain's capacity to change itself over time.

That's not to say life is easy. Wesley requires 24-hour care, seven days a week. But he also goes to see baseball games and enjoys family gatherings. "You can't dictate what is a good life," says Suzanne. "We all face immense challenges. And what may seem hard for one person is not for another. No one should generalize that because a person such as my son can't move or speak and uses a wheelchair and has caregivers.... that it doesn't mean he doesn't want to enjoy his life and be part of something."

Suzanne has gone through her own healing journey since the accident, something known as "post-traumatic growth." As someone who formerly worked 80 hours a week in a stressful, high-powered career, she now has a much different perspective on life. "I sit back and let things happen a little more, and try to appreciate what IS happening," she says. "And I have learned that I can't control the future. But I think, let's embrace any new reality in front of us, and focus on the good we can make from it.

"We live in a 'throw things out' era, where everything's disposable," she adds. "Well, people really aren't. We have trained society to think that you are only valuable if you have a job, and that's not true. People can contribute to society in many different ways. My son brings joy to lots of people's lives, and he gives employment to all his caregivers. Nobody should make assumptions about what a person should be."

"When you love somebody, you go the distance. I love my son as much today as I did seven years ago. He's part of our family and we love having him in our lives." ☞

THE MARK OF STIGMA

In centuries past, stigma was often made visible through physical representations, such as dunce caps (given to students considered "feeble-minded" in the 19th century) or the marks created through a tattooing process given to criminals or slaves in Ancient Greece. In modern times, stigma is more subtle, usually no longer represented by a physical symbol – stigma is simply made apparent through the way someone is treated.



"The minute we tell someone they cannot do something because they are disabled, we disempower them. We take away their desire to have dreams and to achieve those dreams, and we ultimately take away that person's spirit."

- Mathias, Holland Bloorview youth advisory council member, age 22

Expecting people with disabilities to always adjust to a world that doesn't take their needs into account is called **ableism**, a term that is analogous to racism, sexism, or ageism. An **ableist** point of view is centred on a narrow range of "normal" and discriminates against the many diverse ways of functioning in the world. But what if "normal" meant a state where everyone could participate and belong?

Stigma happens when we look at people with disabilities from an outdated and misinformed (ableist) point of view, as inferior and outside the "norm" rather than simply unique – as we all are.

How harmful is stigma?

Daniel Scott meets a lot of children and families in his dual role as children's advisory council lead and outpatient playroom administrator at Holland Bloorview.

He's heard many stories about stigma from the children he works with, but one really stands out – and still makes him sad to this day. A ten-year-old boy was extremely upset because had just learned his family was moving to another country. "He was beside himself that he would have to start from scratch and explain himself to a whole new school's worth of people," says Scott.

"This was a very outgoing, bright, and happy kid, and for him to be exhausted

by this really stuck out to me. When you think about a child's day-to-day life, and constantly being gawked at or having your whole existence questioned – I can't imagine that being your everyday."

Research shows that stigma can have many consequences, such as being seen as responsible for one's own victimhood or not deserving of help,⁶³ and can lead to low self-esteem and other poor outcomes in terms of health and psychological well-being.^{64,65}

"I think often children don't realize they are being stigmatized, but when they do, it really hurts," says Dr. Gibson. "When you're teased or bullied and it's played out to you that you have a difference, that's really emotionally harmful for childhood."

"It takes early training and resilience to rise above a lot of what young people experience as stigma," says Dolly Menna-Dack, clinical bioethicist at Holland Bloorview and former client. Menna-Dack says she's motivated to work with youth because it's an opportunity to create strong advocates in a safe environment – in other words, to foster young people's ability to challenge stigma, including for the benefit of the next generation.

Why do we stigmatize?

"I don't think very young children are intentionally trying to stigmatize people. I think when they ask questions

[about people with disabilities] that otherwise might be considered inappropriate, it is because they want to understand," says Menna-Dack.

"The research on this shows that shaping positive attitudes towards people with disabilities early on is critical," says Dr. Sally Lindsay, senior scientist at Holland Bloorview's research institute, and leader of the hospital's TRAIL (TRansitions And Inclusive environments Lab). "So it's important to reach kids when they're young."

So how do we end up developing negative attitudes about disability as we grow older – and how can we overcome that? "Our own research shows that we're more likely to be attracted to people who are similar to us, and to shy away from people who are different," adds Dr. Lindsay, whose study, "A Model for Developing Disability Confidence"⁶⁶ looks at exactly this phenomenon. "At some point, people need to overcome their discomfort with people they perceive as different from themselves and, once you do that, attitudes can begin to change for the better."

In the extreme cases, lack of knowledge about people different from us results in bullying, cruelty, and other forms of violent behaviour. Dr. Lindsay has done research on bullying that kids with disabilities experience at school and explains she's still haunted by many of

Misconceptions about disability include “a lack of empathy that would allow us to imagine an experience different than our own, and a tendency to overestimate the negative impact of an event and underestimate our own resilience.”

- Daniel Gilbert, Harvard psychologist

the stories that young people told her. It's not just other children who mistreat kids with disabilities either. One story she can't forget is a child who said their teacher put them in the corner of a classroom, activated the locks on their wheelchair, and left them there for a day – without engaging with them at all.⁶⁷

There might be other factors driving stigma. Gert Montgomery, who worked for 39 years at Holland Bloorview (most recently as a senior mentor for the hospital's social work team), talks about how often people have little or no exposure to individuals with any kind of disability, which leads to a kind of unhelpful paralysis. For example, she describes a situation in which a person with a disability looks as if they may need some assistance. "It's not knowing, and worrying about doing the wrong thing, and holding back. Instead of just saying, 'is there something I can do to help?'"

There's also our fear of being vulnerable, or what's been called "the fear factor." "I think we want to pretend that our kids aren't vulnerable, that we, as people, aren't vulnerable," writes Holland Bloorview special projects manager Louise Kinross in the *BLOOM* parenting blog.⁶⁸ "Seeing a child with a visible difference reminds people that ... we're all fragile, mortal and less than perfect."

DISABILITY HATE

Actions and words directed at people with disabilities that are particularly heinous and violent. In a criminal justice context, disability hate crime refers to any criminal act (such as assault, harassment, theft, murder, etc.) where the perpetrator's motive relates to a person's disability. The Criminal Code of Canada requires judges to consider whether a crime was motivated by hate of a victim's disability in sentencing. The Canadian Human Rights Act prohibits the spreading of hatred or contempt against people with disabilities through computers or the Internet.¹⁰⁰

Our discomfort, our fear of being reminded about our own vulnerability, our lack of knowledge, or exposure ... it all leads to misconceptions about disability, often very significant misconceptions. And make no mistake: we all have them. "These include a lack of empathy that would allow us to imagine an experience different than our own, and a tendency to overestimate the negative impact of an event and underestimate our resilience," says Harvard psychologist Daniel Gilbert (as cited in *BLOOM*⁶⁹).

We are all responsible

Stigma can come from anyone. Whether we are young or old, male or female, or identify with one marginalized group or another, we all have biases that we were socialized with as children, and we all have perpetuated stigma at some point in our lives. Research has shown that there is a hierarchy of preference towards disability, whereby people with physical disabilities face less stigma compared to those with other disabilities such as mental illness and intellectual disabilities. Research also shows that stigma happens *within* the disability community. Marginalized groups are not themselves immune from stigmatizing others.

"Even people who think they are very accommodating can stigmatize kids in ways they don't recognize," says Dr. Gibson – and that includes rehabilitation professionals, social workers, and parents. Which underscores the fact that, often, stigma is unconscious.

Dr. Lindsay's research lab at the hospital completed a study that examined supervisors' attitudes towards youth with disabilities in an employment program at Holland Bloorview.⁷¹ In the program, high school students with physical, learning, and cognitive disabilities received work placements, and their supervisors were interviewed afterwards. Many supervisors admitted they were blown away by how much a young person working for them had accomplished – and also ashamed to realize their expectations had been too low in the first place.

It's worth remembering that we all come from the same society – one that doesn't value people with

disabilities and vastly underestimates them. "We're all surrounded by the same notions of disability, so it makes sense," says Dr. Gibson.

"I work really hard not to blame individual kids or parents or clinicians in my work," she adds. "I don't ever say, 'you're doing this wrong; why haven't you figured it out?' Instead I say, 'Of course you're doing it this way. Everything in the world is telling you to do it this way.'"

Negative perceptions

What is common in every instance of stigma is someone's negative perception – a bias that expresses an incorrect assumption. These are the misconceived and usually unstated thoughts playing out in our minds about people who are different from us, mostly in ways we are unaware. Only by exposing and refuting these biases can we begin to change things.

Here are some of the common negative perceptions behind disability-related stigma.

✖ Misconception: Disability is tragic

This phenomenon involves overemphasizing the difficulty of disability or painting it as a burden. "It's that pity, that sorrow, that 'Isn't that sad...,'" says Montgomery. "It's when people say, 'Oh, poor thing.' Or emphasize the absence of a disability by saying, 'We're just glad the baby was born healthy.'"

Under the "disability is a tragedy" notion is the idea that people with disabilities should somehow be hidden, and that disability is shameful.

Occasionally families fall victim to this bias, says Dr. Lindsay. "There are

"I'm always kind of incensed when people ask me what I do for a living, and their first response when I tell them I work with kids who have disabilities is always 'Oh my God! That must be so sad. How do you do that?' It happens on a regular basis, and it's mindboggling to me! My go-to now is to just talk about my work. Most of the time it sparks a good conversation. I love my job! This is the best job I've ever had."

- Daniel Scott, children's advisory council lead and outpatient playroom administrator, Holland Bloorview

some families that hide their child's disability – it's just not talked about, at all. And that's really hard for kids."

Rehabilitation professionals and other service providers can also "hide" a disability, says Dr. Gibson. For example, they might teach a child to cover a prosthesis using clothing so they attract less attention.

"The tricky thing is there's not one right way. It might vary from situation to situation and from child to child, and in some cases that might be the right decision. But I always try to ask, why are we doing that? It may be helpful in a particular situation, but overall is it something that we should be doing, instead of trying to change social attitudes in the long run?"

✖ Misconception: Disability is heroic or inspirational

This sentiment may, at first, appear to be a compliment. Who doesn't want to be considered inspirational? But look below the surface and the underlying assumption can be anything but flattering. The problem is when a person with a disability is described

as "heroic" or an "inspiration" just because they are living with a disability.

Jessica Geboers, who has cerebral palsy, writes in *BLOOM* that: "I've always considered my life to be quite unquestionably normal. This is why I find it odd and a bit sad when I meet people who are surprised to learn that I live away from home with a roommate, study journalism, spent a semester studying and traveling in New Zealand Once people move past their surprise, they often tell me what a great inspiration I am for being so accomplished. But while it's sometimes nice to hear I'm doing well, I hate the implied assumption that people with disabilities don't do these things, and that I am therefore special."⁷²

It's a phenomenon that the late Australian writer, comedian, and disability advocate Stella Young dubbed "inspiration porn" in a 2014 TEDx talk,⁷³ saying that non-disabled people often call disabled people like herself brave and inspirational just "for getting out of bed and remembering our own names in the morning."

Calling a person with a disability "inspirational" in this way ultimately harms and objectifies them for the

benefit of non-disabled people, she says in the talk. It is the equivalent of saying that having a disability must be so horrible or difficult that "overcoming" one by living an ordinary life is inspiration on its own. This in turn makes the non-disabled person feel more grateful, just for being non-disabled. Young says the implied message is, "however bad my life is, it could always be worse."

"It doesn't mean that people with disabilities can't be inspiring in some ways, but not just by virtue of their disabilities," says Dr. Gibson. "It's not just by existing that we should call someone brave."

"We've been sold the lie that disability is a bad thing. And that to live with disability makes you exceptional. It's not a bad thing. And it doesn't make you exceptional."

- Stella Young, TEDxSydney

Misconception: People with disabilities are helpless

People with disabilities often report being treated as if they are helpless, "brave angels," or eternal children. For those who actually are children, they can be even more marginalized, says Holland Bloorview's Daniel Scott, since children are already assumed to be less capable by virtue of their age.

The result can be teenagers treated as if they are five and children spoken to as if they are babies. It can mean kids with disabilities are offered assistance too frequently or not allowed to take risks and explore their worlds.

Paul Alcamo, a teacher at the Bloorview School Authority who has taught classes that integrate children with and without disabilities, says he occasionally observes this in the classroom. "They call it the pet phenomenon," he says. "Sometimes you might see a group of [non-disabled] kids, and they really baby another kid. It's almost like they're playing mommy or looking at the kid as someone who needs taking care of, rather than someone to be friends with. They're being nice, but it's not the kind of interaction that you want to see." He says he works to reverse this by focusing on the child receiving the attention. "I'll say, 'Hey, do you like being talked to this

way? I want you to be telling someone you don't like it if they're stroking your cheek. I want you to be advocating for yourself, and directing your care.'

Infantilizing kids with disabilities or treating them as fragile often extends to those responsible for their care, says Dr. Gibson. "Adults can be super focused on their safety, and it prevents kids from being able to participate in things they want to try."

"The overprotective thing is very common," agrees Dr. Lindsay, noting that it can happen right through to a child's teenage years. "It can be really detrimental to kids, because they don't feel prepared when they're 19 and wanting to go to university

or to get a job and they just don't have those independent skills."

Misconception: People with disabilities have less valuable lives

People with intellectual disabilities are regularly denied transplants in the United States.^{74,75,76,77} A number of pandemic plans around the world stipulate that people with certain disabilities should be denied access to life-saving resources if there aren't enough to go around.^{78,79}

Scientists measure "quality of life" with statistical scores that assume disability lowers life quality (often the scores are determined by asking non-disabled people how they imagine various disabilities might affect them).⁸⁰

And mothers of children with severe disabilities are questioned by friends or even strangers as to whether they had pre-natal testing, the heartbreaking but unspoken assumption being that they would have chosen to abort their child, had they only known.⁸¹

There are so many messages that tell people with disabilities that society values their lives less.

Princeton University philosopher Peter Singer thinks disability can be used as justification for rationing health care. Singer "believes human value is earned by what you do intellectually and physically," and is not inherent, writes Louise Kinross in *BLOOM*,⁸² who calls his views "disability hate."

It is often pointed out that a society that places so much value on work, earning money, and what people "do," misses the point entirely. "It's much better to question traditional notions of



"Almost every semester, there's been at least one professor who questions my disability. I'll go up to them after the first class and hand them an official document from the college outlining the accommodations I need. They'll say, "What is this?" or "Why do you need this?" right in front of the whole class, even though it's stamped "confidential" at the top. I feel like they think I'm faking it."

- Cristina, college student and Holland Bloorview youth advisory council member, age 22

productivity as a measure of worthiness," says Dr. Gregor Wolbring, an ableism and disability studies professor at the University of Calgary, who points out that, for example, many people with spinal cord injuries say their lives are better than ever after their injuries. "It's because they've changed their focus," he says. "Their lives become much more focused on friends and family, rather than being about making money or competing in a job. Unfortunately, society views this as stagnating. It's seen as 'not fulfilling your role.'"

Case in point: a national survey conducted by Holland Bloorview in 2016, which showed that 45 per cent of Canadians believe kids with disabilities lead less fulfilling lives than typically developing kids.⁸³ Actually, research repeatedly shows that people with disabilities report having a high quality of life.

Another case in point is a recent trailblazing study where researchers found a new way to connect with adults with ALS (amyotrophic lateral sclerosis) who were in a completely paralyzed state that prevented them from communicating. Using changes in blood oxygen levels that corresponded with the answers patients gave when answering yes or no questions, the research team was able to discover that the patients repeatedly answered "yes" over a period of many weeks to questions and statements like "I love to live" and "are you happy?"^{85,86}

Many parents and siblings of children with disabilities also seem to develop a new perspective on what is important in life. "No matter what the disability," Kinross explains, "if you think about it from a parent's perspective, their child is their world. That's no different when a child has a disability. You love a child unconditionally, and their value can't even be measured it's so great. You learn very quickly to prioritize what's important – a child's presence – you can't put a price on it."

Misconception: Accommodations aren't rights

This negative perception has to do with the idea that people with disabilities receive unfair advantages or "favours" when their needs are accommodated. And if someone with a disability achieves something significant, the insinuation can be that their success is due to an accommodation they received, rather than coming from their own hard work and talent.

The flip side of this bias is the view that providing accommodations puts a "burden" on others. This is a common perception among employers who do not want to hire people with disabilities (the reality is that the vast majority of job accommodations cost less than \$500⁸⁷). The "burden" argument can also be shared by some parents, who feel their typically developing child's education is somehow compromised by having other

WOULD THEY CHANGE THEIR DISABILITY?

People sometimes assume that those with disabilities would choose to "get rid of" their disabilities if they could – which is not necessarily the case. We asked some of the young people interviewed for this report whether they would change their disability status if they had the choice. Here are a few of their thoughts.

"I wouldn't change a thing. If I had it easy all the time, then I'd never be as strong as I am now."
– Jadine, age 17

"No! Because I am perfectly fine the way I am!"
– Jillian, age 8

"I'm doing great! Yes, I did have a brain injury, but I can manage it, and I'm succeeding! I feel like without a brain injury, I wouldn't be who I am now."
– Cristina, age 22

"There is a part of me that would want to change it. But at the end of the day, this is who I am and I wouldn't change it. I'm proud that my disability has made me more resilient, which has helped me deal with life's challenges."
– Mathias, age 22

"I am a person with a disability that is quite visible to people, and anywhere I go, if I have a person who is an able-bodied person with me, service people direct their questions to them and not to me. Luckily all my friends and attendants immediately say, 'Ask her!'"

- Sandra Carpenter, executive director, Centre for Independent Living in Toronto

children with disabilities accommodated in the same class.⁸⁸ In fact, research shows that typically developing children in classrooms that include students with disabilities show better communication skills, greater acceptance of others, and may show stronger reading and math scores than they would have otherwise.⁸⁹

Misconception: Others can know or speak for people with disabilities

This particular attitude involves people assuming they know what others with disabilities need, are capable of, or are like, without asking them or allowing them to speak for themselves.

The reality is, people are often misinformed about many different diagnoses or disabilities. They may incorrectly assume that all people with a disability such as blindness or Down syndrome do not live independently or are unable to be parents, for example (not true), or that every person who has a physical or communication challenge is also intellectually disabled (also not true). People with a mental illness may be thought of as dangerous or violent, when the truth is that they are much more likely to be targets of violence than perpetrators.⁹⁰ Even within any particular disease or diagnosis, there is a wide range of individual experiences

and abilities, and the only way to really know about a person's disability is by learning from them directly. Sometimes, parents or rehabilitation workers may make decisions affecting children with disabilities without considering their input. For example, in a recent *Toronto Star* article,⁹¹ Dr. Gibson writes about her colleague Crystal Chin, who uses a wheelchair. As a child, Chin spent a great deal of time in therapy trying to learn to walk independently, but "nobody ever asked her if the goal of walking was important enough to spend so much of her childhood trying to achieve it."

On the other hand, Valerie Piro, a woman with a spinal cord injury that resulted from a car accident while she was in high school, writes in *The New York Times*⁹² that she spends hours every morning strapped into an exercise bike with electrical shocks pulsing into her legs. Her goal is to keep her legs healthy in case there is ever a cure for paralysis. "Does spending so much time maintaining my body make me an inspiration, or a disability rights failure?" she asks. "Can I choose a lifestyle that won't be judged?"

Mass media is a large and troubling area where people with disabilities are often spoken for and misrepresented – most commonly through their absence. The lack of people with disabilities on TV, in movies and video games, and in other

mass media reinforces the misconception that they are not part of mainstream society. Too often when characters with disabilities appear, they represent stereotypes, such as inspirational heroes or dependent victims, rather than well-rounded, complex human beings.⁹³ Most concerning of all is the fact that 95% of roles for characters with disabilities are played by actors without disabilities.⁹⁴

And what about news coverage?

According to a report from the Canadian Association of Broadcasters,⁹⁵ there is a lack of coverage of disability issues on television news in Canada. When news coverage does happen, the focus can be distorted. For example, a study⁹⁶ about autism coverage in the *New York Times* showed that while the topic was covered extensively, most stories reduced the topic to a medical discussion, with very few articles describing the discrimination experienced by people with autism or their achievements. The study also found "the voices of people with autism are mostly missing" even in personal stories about autism.

Fortunately, things are starting to shift. Shows such as *Breaking Bad* have cast actors with disabilities in roles that weren't written to be characters with disabilities – a great acknowledgement that people with disabilities are part of society and their disabilities do not always need to be the major focus of their plotline.⁹⁷ Recent series hits like *Speechless* (about a family with a teen who uses a communication device) and *Switched at Birth* (billed as "the first mainstream television series to have multiple deaf and hard-of-hearing series regulars and scenes shot entirely in ASL") are being celebrated⁹⁸ for showcasing realistic characters with disabilities and bringing significant discussions about disability issues into the mainstream.



"We were playing a [dancing game]. I was sitting on the floor dancing. Then some of my friends sat on the floor with me and danced. And it made me feel happy."

- Gavi, Holland Bloorview client, age 6

Aware of difference and inclusion: Gavi's story

"Smart, sweet, sensitive, and sassy." That's how dad Josh describes Gavi, a recent grade one graduate at the Bloorview School Authority in Toronto.

She's also someone who has a full life and a wide variety of interests. Gavi is a sports fan and loves watching basketball, hockey, and baseball on TV with her grandfather. She plays Volt – an accessible form of hockey that uses specially designed power wheelchairs. She takes Hebrew classes. She also loves – among other things – the colour purple, shopping for toys, reading, watching *Full House*, playing board games, and spending time with her parents and older twin sisters.

Gavi was born with nemaline myopathy, a rare muscle condition that affects her gross motor skills and speech. She uses a motorized wheelchair and communicates

using a combination of sign language, a synthetic speech device, and her voice. And at the age of only six, Gavi is "very much aware of her difference," says Josh. Indeed, when she is asked about stigma ("what happens when a person treats someone else in a bad way just because they are 'different'"), she is on-board for the topic right away.

"At summer camp, the kids asked me to say words because they thought that I said the words funny," she says, talking about an experience at a community day camp last year, where she was using her voice to speak. "Sometimes when I'm at the park kids stare at me," she adds. "They think I need more help than I actually do."

She also knows what "inclusion" feels like, describing another camp experience when she felt like she belonged. "We

were playing a [dancing game]. I was sitting on the floor dancing," she says. At the time, the rest of the kids were dancing standing up. "Then some of my friends sat on the floor with me and danced. And it made me feel happy."

Gavi has really enjoyed her three years in school at Bloorview, and she particularly liked art and gym class, her teacher, and the great number of friends she made. She'll be transferring to a public school near home for her grade two year in the fall of 2017. "I am a little bit scared and excited," she confides.

When asked what it's like to have a difference that's easy for others to see, she says, "I don't like it when other people treat me differently because I have a disability. I don't think about it [having a disability] very much. And I like who I am." ☞

The way forward: Inclusion

Sometimes people think that by doing nothing around a person with a disability, they are not causing stigma. The thinking is: I'm not doing anything actively wrong, so how can I be at fault? But many people with disabilities report that doing nothing can cause just as much pain as any other type of stigma – in some cases more so.

"Working to counteract stigma involves more than simply not bullying or not directly treating someone badly. It's active, not passive. People need to make an effort to actually create inclusive and welcoming environments," says Dr. Lindsay.

Ignoring or not including people with disabilities in regular activities is called **exclusion**. It's not right, and it can cause considerable harm. Here are just a few examples:

- No one invites a child with a disability to play at recess.
- A child with a disability and her family take a walk in a local park. No one acknowledges them, including people they have seen many times before around the neighbourhood.
- A parent knows their child has a classmate at school with a disability, but never uses it as an opportunity to talk to their child about the boy's disability or who that classmate is beyond his disability.
- A teacher creates a game, and instead of adapting it so the whole class can be involved, she gets two students with disabilities to play by themselves off to the side of the room.

"I think the worst anyone can do is to ignore me."¹⁰¹

- Andre Arruda (1983-2017), actor, comedian, and disability advocate

All stigma directed at people with disabilities is ultimately exclusionary – it prevents someone from having the experience of leading a regular life. The opposite of stigma, therefore, is inclusion, where people take proactive steps to welcome people with disabilities in everyday activities, and ensure they have a way to participate that accommodates their disability if needed.

To learn more about inclusion and helpful resources to promote it, please see "About Holland Bloorview Kids Rehabilitation Hospital" on page 22.

Time for an attitude adjustment

There is so much to do, and no time to waste. All of us have an urgent responsibility to help when it comes to changing the way society treats children and youth with disabilities – whether we are a parent, an educator, a classmate, someone who provides services to young people with disabilities and their families, an employer, a government decision-maker, or a member of the public.

The place to start is by taking a good look within. Because behind every barrier is someone's attitude that placed it there. Attitudes create actions (or inactions) that shape our world.

The question is, what attitudes do each of us need to change before nearly half a million young Canadians with disabilities can feel like they belong? What needs to shift before these children and youth can realize the future they deserve, one of boundless possibilities? And what can each of us actually do now, and do differently, to make a difference?

It's time for an attitude adjustment, Canada. And all of us need to get on board.

Section 3:

Key recommendations and actions for change

Young people with disabilities can no longer afford to wait for the very slow march of progress before they realize the future they deserve.

For that to happen, every one of us needs to get involved. The time to act is now.

With this in mind, Holland Bloorview Kids Rehabilitation Hospital offers these key recommendations and actions for change to address the stigma faced by Canadian children and youth with disabilities.

Key recommendations:

- **Self-reflect on your own bias, both conscious and unconscious:** We call on everybody across Canada, including allies, parents of children with and without disabilities, educators, employers, and health-care providers, to look inward and challenge their own attitudes and behaviours about disabilities to help end stigma.
- **Ensure decision making includes disability:** We call on all policy makers and elected officials to consider the needs and wants of children and youth with disabilities in any decision making, conversation, or activity impacting children and youth. Children and youth with disabilities and their families should participate meaningfully in the policy development and decision-making processes.
- **Embed disability awareness in health care:** We call on health-care organizations to ensure their employees have thorough training in disability issues, stigma, and health equity to ensure that people with disabilities receive the highest quality of care to help them reach their goals. Children and youth with disabilities and their families should participate meaningfully in the development of these training programs and resources.
- **Make disability part of education:** We call on each province to ensure every teacher and aspiring teacher has thorough, mandatory training in disability issues, ableism, and stigma. In addition, education about disabilities, stigma, and inclusion should be a mandatory part of the curriculum for students. Children and youth with disabilities and their families should participate in the development of the training and curriculum.
- **Harness disability in employment:** We call on employers large and small to actively recruit youth and adults with disabilities and seek support from employment organizations/agencies about best practices for hiring and creating inclusive workplaces.

Actions for change:

Take action now. Download our actions for change tipsheets for parents/guardians, allies, health-care providers, employers, educators, and media professionals at deareverybody.ca



(see Appendix A for full tipsheets)



About Holland Bloorview Kids Rehabilitation Hospital

Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) is a leader in helping young people with disabilities and their families to build resilience and achieve a world of boundless possibilities. Our research, inventions, and evidence-informed practice guidelines impact the lives of children and youth around the globe.

Our efforts are guided by a goal to **lead and model social change** by advancing awareness and deep acceptance of disability as part of diversity. Key initiatives in this area include our work to collaborate to influence public policy related to inclusivity in schools, workplaces, health care, and transportation, and to model inclusion in everything we do.

Holland Bloorview is a global leader in client and family centred care. Our **Family Leadership Program**,¹⁰² for example, consists of volunteer family members who sit on dozens of internal and external special projects, among their many other contributions. Holland Bloorview also has **youth and children's advisory councils**,¹⁰³ where young clients provide critical input into the development

and evaluation of our research, teaching, programs, and services, and have the opportunity to share their voices and develop self-advocacy skills.

Many of Holland Bloorview's applied **research**¹⁰⁴ programs contribute towards a greater global understanding of stigma and resilience, and influence public policy and practice. Our research work in stigma looks at young people's experiences with inclusion, friendships, life transitions, and bullying, and the attitudinal and other barriers they may experience in education, health care, employment, and other settings.

Holland Bloorview's extensive hospital services and other programs help build young people's participation, inclusion, and resilience in society. We have a number of innovative life transition programs such as our **post-secondary program**¹⁰⁵ and **work placements**.¹⁰⁶ We also develop tools, programs, and resources to foster inclusion in society; our freely available **Classroom Integration Workshop Toolkit**¹⁰⁷ for example, contains a complete hands-on workshop plan to help teachers build their capacity to offer meaningful, inclusive education

opportunities in the classroom. Other resources include our **Peer Support Best Practices Toolkit**,¹⁰⁸ **Care for the Caregiver hub**,¹⁰⁹ and **online resource centre**¹¹⁰ with tipsheets and information covering a range of topics from growing up to managing money. Resources such as our **Quality Improvement Plan overview just for kids**¹¹¹ reflect our clients' needs and aspirations, and clearly articulate the improvements they can expect from our hospital each year (our children's advisory council has input into the development of this annual plan).

Holland Bloorview is Canada's largest children's rehabilitation hospital and is also an academic hospital fully affiliated with the University of Toronto. We focus on improving the lives of kids with disabilities, kids needing rehabilitation after illness or trauma, and kids whose medical complexity requires specialized care. We serve nearly 7,500 children and youth annually, accounting for more than 1,000 unique diagnoses. We serve families from across Ontario, Canada in our inpatient units and specialized medical clinics, and provide outpatient therapy and recreation for families in the Greater Toronto area.

Glossary

Ableism: In the context of disability, ableism is a bias that describes the expectation that people with disabilities should have to adjust to the “non-disabled” world and that this is a “normal” state, rather than seeing “normal” as a world where everyone can participate and belong. Ableism sees people with disabilities as inferior to others. The term ableism is the equivalent of terms such as “sexism,” “racism,” and “homophobia.”

Disability hate: Describes instances of stigma against people with disabilities that are particularly heinous and violent. In a criminal justice context, disability hate refers to any criminal act (such as assault, harassment, theft, murder, genocide, etc.) where the perpetrator’s motive relates to a person’s disability.

Diversability: Describes the fact that the world is full of a wide range of different human abilities that manifest differently in different people.

Exclusion: In the context of disability, exclusion happens when a person with a disability is ignored or not given a chance to participate in something that they should be able to participate in.

Inclusion: In the context of disability, inclusion means taking action to involve and welcome people with disabilities in everyday activities, and ensuring they have ways to participate that accommodate their needs.

Inspiration porn: Describes instances where someone with a disability is called “heroic” or “inspirational” not because they have done something truly remarkable, but because they are living a regular life with a disability.

Intersectionality: Describes the fact that there are many overlapping identities and related systems of discrimination (such as ableism, racism, sexism, and classism) that combine, overlap, and intersect in the experiences of marginalized people or groups.

Invisible disability: A disability that is not visible to others. Learning disabilities, brain injuries, and mental illnesses are some examples.

Stigma: The shame or inferior status that people consciously or unconsciously ascribe to others they perceive as different from themselves. Underlying stigma are negative perceptions or attitudes about disability that are based on outdated and incorrect assumptions.

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Thanks also to those we spoke to who wish to stay anonymous.

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Appendix A:

Tipsheets (see following pages)

Ways you can help kids and youth with disabilities reach their goals

Recognize

kids and youth with disabilities can help YOU grow.

Understand

that part of your role may involve developing new skills to better support and advocate for your child.

Support

kids and youth with disabilities in identifying and reaching THEIR life goals.

Encourage

kids and youth with disabilities to participate in recreation, work, or volunteer activities to help them build friendships and life experiences.

Celebrate

our differences!

ONLINE RESOURCES

[Care for the caregiver hub](#)
[Online resource centre](#)
[Workshop calendar](#)
[Community programs](#)

Expect a lot

from kids and youth with disabilities when helping them create good lives.

Assist

kids and youth with disabilities in taking calculated risks to achieve their goals.

Help

kids and youth learn how to communicate with others about their disability and advocate for their needs and goals when they choose.

Discourage

stigmatizing kids and youth with different types of disabilities than your child.

Appreciate

that goals can change or be adapted over time and that is okay.

Build

on your child's strengths and goals rather than focusing exclusively on disability.

Nurture

and develop social networks with people who have common interests and who can be allies to your family.



Holland Bloorview Kids Rehabilitation Hospital believes in creating a world where every child and youth belongs. In partnership with our clients and families, we call on everybody to take action to end stigma of children and youth with disabilities.

Each person with a disability is unique and some of these actions may need to be adjusted to best support individual needs and wants.

Ways you can be an ally for kids and youth with disabilities

Challenge

the assumption that kids and youth with disabilities lead less fulfilling lives.

Understand

that disability is part of life and should not be viewed as inherently tragic or inspirational.

Listen and learn

from the experiences of kids and youth with disabilities.

Consider

the person first, before their disability. Disability is just one part of a person's identity.

Teach

those around you that difference is valuable and part of being human.

Actively

invite kids and youth with disabilities to join your social and community activities.

Share

the message that kids and youth with disabilities belong in your community, classroom, and workplace.

Stop

using negative and 'ableist' language, like "confined to a wheelchair" or "suffers from a disability" that implies having a disability is bad. Instead use, "uses a wheelchair" or "has a disability."

Respect

how each individual chooses to describe themselves and their disability. For example, some people use "autistic person," while others use "person with autism."

Celebrate

our differences!

Take accountability

to prioritize and support diversity in your life and take action when you witness stigma and exclusion.

Self-reflect

about your own views about disability and acknowledge your own biases and exclusionary actions.



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Each person with a disability is unique and some of these actions may need to be adjusted to best support individual needs and wants.

Ways you can help kids without disabilities become allies of people with disabilities

Teach

kids that difference is valuable and part of being human.

Talk

about different types of disabilities and what we all have in common.

Discuss

with kids how everyone (classmates and friends) can work or play together and encourage those connections.

Share

the message that kids and youth with disabilities belong in your community, classroom, and workplace.

Help

kids avoid negative and 'ableist' language, like "confined to a wheelchair" or "suffers from a disability" that implies having a disability is bad, and instead use "uses a wheelchair" or "has a disability."

Encourage

kids to ask questions about disability, including asking kids and adults with disabilities directly. Teach kids how to use respectful language and to seek permission before asking follow up questions.

Explain

that each individual chooses how to describe themselves and their disability. For example, some people use "autistic person," while others use "person with autism." The best way to understand how an individual wants to be described is to ask them.

Ask

kids about times they have felt different and reflect on those experiences.

Celebrate

our differences!

Identify barriers

(like stairs, videos without captions, or doors without access buttons) and talk to kids about how we can find solutions.

Actively

invite kids and youth with disabilities to join your social and community activities.



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Each person with a disability is unique and some of these actions may need to be adjusted to best support individual needs and wants.

Ways you can create workplaces where young people with disabilities belong

Seek

support from ally employment organizations/agencies about best practices for hiring and creating diverse workplaces.

Make

it clear on your job postings that you are an employer who values diversity and recruits young people with disabilities.

Recognize

that in many cases accommodations for young people with disabilities are not expensive.

Celebrate

our differences!

ONLINE RESOURCES

Holland Bloorview employment programs

Ensure

young people with disabilities have meaningful opportunities to advance and take leadership roles.

Connect

young people with mentors who have disabilities and work in their areas of interest.

Create

a workplace culture that celebrates disability as an important part of life and values the unique contributions of all employees.

Educate

other staff in the workplace about disability, respectful language, and tools or strategies to help the whole team succeed.



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Each person with a disability is unique and some of these actions may need to be adjusted to best support individual needs and wants.

Ways you can help young people with disabilities find employment

Communicate

with your teen about their interests, strengths, and sources of motivation.

Encourage

your teen to participate in activities (recreation, volunteering, co-op programs) that help them identify their employment goals.

Discuss

and support your teen's decisions about when, if or how much they want to work.

Learn

how to job search and support your teen with weekly job search goals.

Practice

life skills with your teen, such as making choices, problem solving, managing stress, navigating transportation, and communicating.

Support

your teen with establishing routines (making lunch at night, planning transportation).

Connect

your teen with supports like job preparation classes and workshops.

Research

with your teen educational and post-secondary programs through colleges or universities that support people with disabilities.



ONLINE RESOURCES

Holland Bloorview employment programs

Holland Bloorview Kids Rehabilitation Hospital believes in creating a world where every child and youth belongs. In partnership with our clients and families, we call on everybody to take action to end stigma of children and youth with disabilities.

Each person with a disability is unique and some of these actions may need to be adjusted to best support individual needs and wants.

Ways you can support kids and youth with disabilities reach their goals

Understand

that disability is part of life and should not be viewed as inherently tragic or inspirational.

Expect a lot

from kids and youth with disabilities when helping them create good lives.

Listen

and actively seek input from kids and youth with disabilities in goal setting and decision making.

Encourage

kids and youth with disabilities to take calculated risks to achieve their goals.

Plan

examination and treatment spaces to accommodate supportive equipment.

Discuss

with kids and youth with disabilities what they like to do and incorporate those activities in their treatment and home programs.

Support

a healthy balance between therapeutic goals and other life goals.

Help

kids and youth learn how to communicate with others about their disability and advocate for their needs and goals when they choose.

Build

on strengths and goals rather than focusing exclusively on disability.

Celebrate

our differences!



ONLINE RESOURCES

[Key behaviour tipsheet for health-care providers](#)

[Best practices peer support toolkit](#)

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deareverybody.ca

Holland Bloorview
Kids Rehabilitation Hospital

Ways you can create classrooms where kids and youth with disabilities belong

Understand

that disability is part of life and not inherently tragic or inspirational and as an educator you are uniquely positioned to help students re-think their understanding of disability.

Expect a lot

from students with disabilities when helping them create good lives.

Listen

and actively seek input from students with disabilities in goal setting and decision making.

Learn

what your students with disabilities like to do and incorporate those activities in the classroom.

Adapt

group activities (such as field trips and sports) so all students can participate, without exception. This means all students participate in the same activity and use their strengths to contribute to the activity's success.

ONLINE RESOURCES

[Classroom integration workshop toolkit](#)

Help

students learn how to communicate with others about their disability and advocate for their needs and goals when they choose.

Include

curriculum content created by or for people with disabilities so all students see themselves reflected in the classroom.

Make

every day a new opportunity to build on the strengths of students with disabilities who are experiencing challenges.

Foster

a climate of acceptance, belonging, friendship, and kindness in your classroom and school.

Recognize

all forms of bullying and address them.

Ensure

students receive all supports they require in their accommodation plans.

Plan

physical spaces and desk arrangements to accommodate supportive equipment and different learning styles.

Consider

using accommodations like visual schedules for the entire class, instead of exclusively for students with disabilities.

Identify

barriers, like doors without access buttons, and discuss how we can find solutions.



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Ways you can create inclusive media coverage for kids, youth, and adults with disabilities

Understand

that kids, youth, and adults with disabilities lead fulfilling lives and that disability is not inherently tragic or inspirational. It is important to shape media coverage to reflect that.

Seek

people with disabilities' own voices, perspectives, and experiences in stories and news coverage. It is important the members of the disability community have the opportunity to shape public discourse about disability and other topics.

Avoid

negative and 'ableist' language, like "confined to a wheelchair," "wheelchair bound" or "suffers from a disability" that implies having a disability is bad. Instead consider "uses a wheelchair" or "has a disability."

Ask

the person who has a disability questions directly, rather than asking the person they are with.

Respect

how each individual chooses to describe themselves and their disability. For example, some people use "autistic person," while others use "person with autism." The best way to understand how an individual wants to be described is to ask them.

Consider

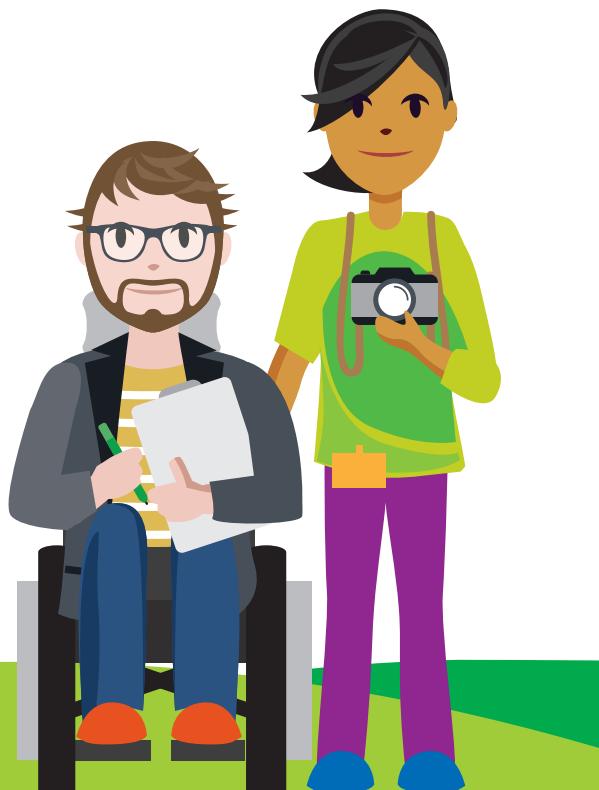
the person first, before their disability. Disability is just part of a person's identity. Dive into their story. Learn who they are.

Hire

people with disabilities in the newsroom and on-camera. The media is uniquely positioned to shape public perceptions and build awareness about disability issues and it is important the voices of people with disabilities help shape and tell those stories. Make your newsrooms inclusive and accessible.

Familiarize

yourself with guidelines such as **Media Smart's Media Portrayals of Persons with Disabilities: Solutions** and **The Canadian Association of Broadcasters' Equitable Portrayal Code**.



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