

## The Listening Tour

Since the 1970s, when children with disabilities were routinely denied access to schooling, Canada has made significant strides in inclusive education. Today, the more than 200,000 children and youth living with disabilities in Canada attend school, many in integrated classrooms with their able-bodied and/or neuro-typical peers. Despite such progress, changes in public education have been insufficient to ensure children living with disabilities have the same access to quality education as their peers. Research indicates that a pervasive lack of resources, information and awareness persists in keeping children living with disabilities in many ways segregated. The 2012 Canadian Survey on Disability found that bullying and exclusion remain widespread throughout Canada's educational system, with one in four students with disabilities reporting being bullied and/or avoided or excluded.. The survey further found that 16% of students living with disabilities have had to change schools and over 10% reported that barriers within the school system prompted them to discontinue their education early. Furthermore, according to a 2012 University of Windsor study, 53% of children with disabilities reported having no friends.

*“Social isolation is prevalent amongst children and youth living with disabilities. In a study conducted in 2018, evidence showed 53% of children and youth living with disabilities had no friends.”*

The Globe and Mail, 2018

In early 2020, Jays Care began a Listening Tour with parents and/or guardians across the country involved in Challenger Baseball in an effort to learn about their experiences and challenges with the education system so that we could improve our delivery of Challenger Baseball in schools and communities throughout Canada. More than 75 families generously contributed their time, painful and positive personal experiences, and concrete suggestions to promote inclusivity. What emerged from those conversations is a series of letters addressed to the people most involved and influential in the lives of children and youth living with disabilities: educators, community programmers, parents, and government policymakers.

These letters are intended to be informative and challenge recipients to rethink the way they interact with children living with disabilities and their families. We also hope that the stories and testimonies presented here will demonstrate the influence recipients are capable of having in shaping the lives of such children and inspire them to continue doing invaluable work to create a more inclusive Canada.

Thank you to all those who made these letters possible; above all, to all of the families who shared their experiences. We'd also like to acknowledge the 10 families who reviewed, revised and edited these letters so they best reflect their collective voice and opinions. Thank you to Joshua Vatcher for being our lead listener and note-taker in countless interviews, and to Matt Demita for pouring through thousands of quotes, survey responses and interview notes to help find the most common themes and ensure that the true voice of families is reflected. Finally, our sincerest thanks to you - the educator, programmer, parent, guardian and government decision-maker who has made creating a more inclusive Canada a part of your day-to-day mission.

*“It's nice to know that someone's listening – change is possible.”*

*“The community of special needs, in general, don't get the right support.”*

## Dear Educators,

Teachers have the potential to act as advocates and mentors for students living with physical and/or cognitive disabilities, and our conversations with parents, guardians and Challenger Baseball athletes demonstrate that they can serve as a tremendous source of support when given the resources required by the young people in their care. According to those we spoke with, while many individual educators are doing exemplary work, there are several common issues that schools and school systems must address to better support all students moving forward:

### **SUPPORT IS KEY TO INCLUSION:**

Overwhelmingly, the parents of students with disabilities we spoke to simply want their children to be involved in the classroom and to share the same social, physical and academic pursuits as their able-bodied and/or neuro-typical peers. This often requires some form of specialized support, such as adaptive equipment or additional trained staff. When schools can provide these resources, students excel:

- *“School is amazing, he has an EA. Teachers and EAs integrate him with all the other kids and make sure he is included. Cullan occasionally gets pulled from class to do his work with his YSF... Cullan is a celebrity, everyone wants to be with him, and they even take turns pushing his chair.”*
- *“...[the] principal is a huge advocate for special needs and other issues. Very accessible and needs are being met!”*

In the absence of such support, children with disabilities often remain marginalized and isolated:

- *“[The] school system was awful; they wouldn’t support Hayden. I used my job as a teacher to help accommodate Hayden.”*
- *“Everything, especially early on, that Elliot received at school was due to me fighting and advocating for it. Once I camped outside of [an] office to get Elliot his own EA so that he could be integrated in learning with his peers.”*
- *“...you can’t get the support, funding just isn’t there, they were doubling up on EA’s instead of focusing on the individual approach.”*

*“Eric has 1-1 EA support (has had that since kindergarten) – fully integrated in his classroom. Supplemented learning but his area is right in with everybody else. He does quite well in the classroom... his growth is slow but definitely progressing. His classmates love him, it’s a really positive environment. The whole school is very great at anti-bullying and inclusion.”*

*“With COVID-19 the world has gotten a bit of a taste what autism, OCD, ADHD brains feel on any given day. This is why routines are so important. Aidan has struggled but I feel his EA and school has done the best to keep in touch, video chats, sending emails with little videos from them etc.”*

*“It is my belief that student teachers should be better prepared to enter their classroom teaching job ready to work with children with special needs and their programs. Being caring and compassionate is a must. Focus on empowering, not enabling. Focus on the positives. Set goals. Celebrate successes.*

*Classroom teachers need to teach their students how to appropriately communicate/interact with the child/children with special needs. Teachers must lead by example.”*

### **SET HIGH EXPECTATIONS:**

Like any parent, those we spoke to want teachers to help their children realize their full potential, and both students and parents/guardians alike believe it's critical that educators set high expectations for students living with disabilities in their classrooms. Teachers and EAs who believe these children are capable of accomplishing lofty goals are more likely to help them to do so. Conversely, those who set low or no expectation for such students offer little encouragement or motivation, resulting in lower achievement and reduced self-confidence.

*"Don't do the work for him. Push him like you would the other kids. Don't baby him. He can take it. Sometimes you can find that some people will dumb stuff down – because they think that they are helping him – but he can handle the same expectations as other kids."*

- *"Just include him, treat him like anyone else. Don't look at the disability first."*
- *"He picks up more than we give him credit for. Help him become more and more independent."*
- *"Some EAs babysit...Only two of his many high school teachers were hands-on and actually cared for Hayden, which was terrible for him. This, in turn, made Hayden hate school and have behavioural issues due to the lack of support."*
- *"As long as people are open-minded and don't mistake her for lack of intelligence based on her being in a wheelchair. Kids are more accepting; adults do not see her full potential."*

### **CREATE LOTS OF OPPORTUNITIES TO CONNECT WITH PEERS:**

One of the deepest aspirations of the parents, guardians and children we spoke to is to develop meaningful relationships with peers, both at school and beyond. Loneliness and isolation are troublingly common experiences for children living with disabilities and their families, and for many, school is their only opportunity to socialize. When teachers make of point of helping socially isolated students forge supportive relationships, the benefits in both the near and long-term are profound and can transform a child's outlook about their surroundings and themselves.

*"My biggest wish for my child is for her to be able to fully participate and feel like she is part of a team. Make new friends and boost confidence in herself!"*

- *"Owen loves school and he has been well accepted by the school community. He needs a lot of support to help him interact with the other students in the school..."*
- *"They encourage him to play/socialize with other kids. They try to include suggestions from his speech/OT/PT in his daily routines. They help him to be independent as much as possible."*

Sadly, social stigma around disabilities remain pervasive and many children with living with physical and/or cognitive disabilities continue to be ignored and neglected by teachers and peers who don't understand how to engage with them or recognize the importance of doing so.

- *"I don't think Aidan's lack of friends is a program issue – I think it's a stigma issue. He's in grade 4 now; he's got limited words, and it can be hard to understand him, and Aidan often doesn't understand the boundaries. He wants to get invited to birthday parties and playdates, but he never gets invited."*
- *"Making friends is one of his biggest challenges because of his intellectual impairments. I think he really wants to – he tries his best as non-verbal (smile, poke) or say something that's funny but it's a huge, huge challenge."*
- *"She can't make friends because of the stigma that surrounds her, and it's put on her by others."*

Below are the most common responses we heard when asking parents to complete this sentence: **“My biggest dream for my child is.....”**:

- *to be included, and get the same opportunities as his peers*
- *to have fun and make friends*
- *to feel included and part of a community*
- *to make good friends*
- *to have fun, make friends*
- *to have fun, to meet new friends that he just clicks with (i.e. develops great friendships)*
- *just to be happy and makes friends along the way*
- *for Ryder to develop more independence and genuine friendships with peers*
- *to have fun, make friends,*
- *to make new friends, feel involved.*
- *to be happy and feel included.*
- *for her to have fun and be accepted.*
- *for him to socialize more with peers his age and make friends*
- *to have fun and make friends and generally have a happy life.*
- *to have fun, to meet new friends that he just clicks with (i.e. develops great friendships)*

### **ADAPT THE CURRICULUM SO ALL CAN PARTICIPATE:**

When schools and teachers have the flexibility and resources to adapt coursework to meet their needs and interests, students living with disabilities thrive, according to parents/guardians.

*“In the past few years gym class has been a struggle because teachers cannot adapt the curriculum. She is physically unable, and if it can’t be adapted then she has to use walker in.”*

- *“School is working hard to accommodate his needs, they are working on getting him adaptive technology.”*
- *“Breanna’s school offers an inclusive environment and goes above and beyond to raise awareness for people with disabilities. During the first semester, the school brought in a large supply of wheelchairs and wheelchair sports were played during phys. ed. along with wheelchair sports for intramurals.”*

All too often, however, budget constraints, limited or lacking equipment and insufficient or lack of training prevent educators from adequately adapting curricula to accommodate students living with disabilities, particularly in physical education. The result, sadly, is that many parents and guardians spoke of their children routinely being excluded from classes and/or classroom activities.

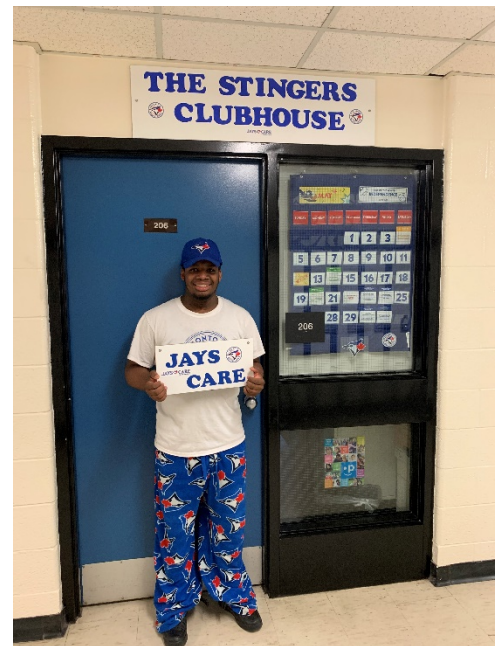
- *“They don’t know how to adapt programming to meet her needs and keep a safe environment, so she ends up doing physical therapy outside of the gym with a support worker and another student.”*
- *“I noticed he’s always included in class activities but when they do an activity that he can’t do he always gets one-on-one time with another teacher.”*
- *“We wish there was more support around Speech services (gets almost nothing at school).”*

## **BUILD AWARENESS AND UNDERSTANDING OF BEHAVIOURS AND NEEDS:**

Parents, guardians and students told us about their unique strengths, challenges and their frustrations about common misconceptions surrounding their behaviours. According to parents/guardians, many teachers and EAs are generally unfamiliar with common behaviours of these students and thus are ill-equipped to respond to or prevent behaviours their children can exhibit. Furthermore, few have substantive experience preparing appropriate programming or adapting lessons to suit the needs and abilities of children with disabilities. Many parents/guardians advocated for providing teachers with robust training in adaptive education techniques to broaden their understanding of the needs of their students and better prepare them to lead more inclusive classrooms.

- *“Train the staff. The experience was far from enjoyable, staff relied on the parents to cater to their children, it was evident this was their first experience with special needs kids.”*
- *“Make sure the staff are trained in how to support kids with disabilities. The first session at our rec centre was led by a new staff member who seemed like he had inadequate training to deal with special needs children, it was bad.”*
- *“The frustration was that people really misunderstand him. When you look at him, you wouldn’t think that he’s a child with special needs. He doesn’t have any physical disabilities. We had a very hard time with our old VP and Principal – we now have a new VP and Principal and a new male EA. All of them have taken the time to understand what he needs to succeed and what he needs to thrive at school and in life.”*

*“I found, at least in our school, the people who are in charge of special education students seem to have challenges, they do not really understand or can’t relate. If they never raised their own special needs child, then they just do not get it. The training they do receives seems incomplete, seems there are gaps and they do not know how to handle certain situations.”*



## **INCLUSION IN EXTRA-CURRICULAR SPORTS:**

Parents, guardians and students consistently lauded the benefits of adaptive sport programming, stating that inclusion on a team, building social relationships and developing athletic skills helped immeasurably to build students’ self-confidence. The demand for additional programming is evident as many parents/guardians shared that adaptive recreational opportunities are scarce, if not entirely inaccessible in certain areas. Schools that have created extra-curricular programs designed for children living with disabilities as well as those that adapt activities so that all students can participate were celebrated, and parents/guardians expressed a strong desire for more school-based sport programming.

*“He’s not involved in any extra-curriculars/after school programs – not on any sports teams. We wish there were more programs available.”*

- *"I wish there were more adaptive sports opportunities. [There are] not enough spread out across the country... not enough word being put out about these programs. Special ed kids need to be made more of a priority and that's not okay."*
- *"Our kids want to have some of the experiences that regular kids get and we don't feel that there's enough offered."*
- *"He loves when he's really included in real sport. When the level of the game isn't just 'we are entertaining kids with special needs.' He likes it rough and competitive and it demonstrates that kids with disabilities can play hard and work hard and be great contributing members of society."*
- *"Challenger[Baseball] has made the world a difference - found out [about it] from a friend who needed players, registered and went in knowing nothing. It allowed us to feel like regular parents, and the kids feeling success, for every single kid no matter what the barrier, it gives us the moment to feel normal and unjudged."*



"My biggest dream is for my child is...."

- *to be included into everything they wish to learn. To remove any obstacles that may hold them back from playing anything that they wish to play."*
- *to experience being a member of a sports team*
- *to consistently able to attend a sports activity once or twice a week with other special and typical peers.*
- *to do what he enjoys. He loves sports-basketball, baseball, hockey.*
- *to be motivated to be physically active!*
- *to help mentor younger athletes so they can see the impossible is always possible.*
- *to continue to play baseball*
- *to enjoy a recreational activity with his peers.*
- *to feel that he is part of a team and can contribute to supporting teammates.*
- *to be a team player, support his friends and teammates, be a leader on his team*

## **CONSIDER THE ACCESSIBILITY OF SCHOOL FACILITIES:**

While there have been vast improvements in the accessibility of schools in the past decades, parents/guardians said that physical and linguistic barriers in many school buildings persist in preventing students living with disabilities from meaningfully integrating with their peers. Parents/guardians felt that educators and administrators are often largely unaware of these obstacles and would be better equipped to advocate for and create positive change if they were conscious of the nature and number of barriers students living with disabilities face in a day. Many suggested that school leaders conduct a thorough assessment of their facilities, from entry to exit, to better understand where accessibility improvements are needed.

*"If you take the time...the small details...they have a trickling effect and they have big outcomes."*

- *“Accessibility is a huge issue anywhere and everywhere.... there are many places, like even simple places like restaurants, that aren’t [accessible]. For example, on restaurant you have to go through the back, in the kitchen – no one wants to do that.”*
- *“Accessibility, whether physical, language, emotional...would make a large difference for many people...funding is so bad, everything is being cut.”*

## **DISPLAY COMPASSION FOR PARENTS AND GUARDIANS**

When asked about their experience as parents/guardians of children living with disabilities, those we spoke to consistently described feelings of loneliness and isolation. Many mentioned financial and logistical obstacles making it challenging to maintain social connections, and more profoundly, the inability of friends and family to truly comprehend the realities of raising a child with complex needs..

*“It has been very isolating...[I] can’t go out with friends, financially, and they don’t understand.”*

- *“It’s been very isolating... I’ve lost many friends because the situation, or the time investment, of having to plan your life according to Aidan’s needs...When he was younger, we didn’t know if getting sick meant something detrimental to his future...it’s hard to be with people when you’re fearing germs.... It’s hard to expect somebody to fully “get” your life when they don’t live it. The biggest thing is understanding the stigma that goes around – I even get it from family. People believe that we just need more discipline, or more structure – they don’t get that it’s because he has autism.”*
- *“Yes, it is isolating. I have formed friends with parents in similar situations, we get together and de-stress and attend workshops on parenting a child with special needs. My friends with typical children have more freedom than I do. It takes lots of pre-planning to get together. I have to work around Hayden’s schedule.”*
- *“They don’t know what it’s like to raise a child with a disability most times. They do not recognize they are also regular people, attaching a pity or negative stigma instead, such as misconceptions like they don’t understand what you’re saying.”*

## **OFFER CONTINUING SUPPORT THROUGHOUT HIGH SCHOOL:**

Many parents/guardians were distressed to find the support networks they fought so hard to create in lower years were no longer available when their children entered high school, and many students struggled to adjust to an environment with less individual attention, care, and accommodation from educators. Recognizing that high school is a time when students are typically expected to demonstrate greater autonomy, parents/guardians expressed the need for more adaptive curricula that would enable students living with disabilities to thrive in a less structured atmosphere.

- *“We have developed a system that has become a one-size-fits-all approach. Although different diagnoses have different streams and so on, not every child within those streams are the exact same, therefore the same principles and guidelines may not apply to them. Educators need to spend more time paying attention to each child’s needs and take the time adapting it to them.”*
- *“High school was challenging for both Hayden and his mom, trying to ensure that his EA’s developed learning strategies for Hayden as opposed to “babysitting.” There was nothing post-high school to help find a path after, no advice or advocacy to help to continue in life.”*

Our conversations with parents, guardians and students across the country revealed that systemic physical and cultural barriers in public education deprive many Canadian children living with disabilities of the same academic, social and athletic growth and development typical children enjoy. Such disparities in the educational experiences of children living with disabilities have lasting consequences on their prospects in adulthood, often leaving children with complex or atypical needs less prepared for the workforce, less capable of living autonomously and less civically engaged as adults. While every province has committed to inclusive education, as parents/guardians can attest, more needs to be done to ensure that children living with disabilities are fully integrated into school systems. We urge you as educators to consider what could be done to make your classroom and school more inclusive and to advocate tenaciously for the resources required to support every student in your charge. We are committed to a Canada where every child has access to a quality education that prepares them for success, and improvements in inclusive education lay the foundation for children living with disabilities to be more self-reliant as adults and lead more dignified, fulfilling lives.