NOTHING ABOUT US WITHOUT US

PERSONAL NARRATIVES OF DISABILITY FROM THE NORTHWEST TERRITORIES

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Introduction

The Northwest Territories is a vast and sparsely populated region in northern Canada, covering over 1.3 million square kilometers of land. The territory is home to diverse landscapes, including rugged mountains, boreal forests, tundra, and Arctic coastline. The population of the Northwest Territories is relatively small, with just over 44,000 people residing in the region, most of whom live in the capital city of Yellowknife and the remainder in smaller communities. Over half, 50.7%, of the population is Indigenous, consisting of Inuit, First Nations, and Métis peoples. The climate in the Northwest Territories is characterized by long, cold winters and short, mild summers, with temperatures often dipping well below freezing for much of the year.

In the Northwest Territories, daily life can be challenging even for the non- disabled. For those living with disabilities, these challenges can be magnified many times over. Yet, despite the obstacles they face, people with disabilities in the territory have carved out lives of remarkable resilience, determination, and creativity.

This book is a collection of first-person narratives from individuals and families living with disabilities in the Northwest Territories. Through their stories, we gain a unique insight into the daily struggles and triumphs of the northern disability community. From negotiating and overcoming barriers in health care, education, housing, employment, social inclusion, and intersectional challenges, these stories highlight the challenges, resilience, resourcefulness, and ingenuity of people living with disabilities across the Northwest Territories.

Sharing first-person stories takes courage and vulnerability. We commend the bravery it takes for individuals to open up and share their personal experiences. We wish to express our deepest gratitude for the willingness of contributors to share their life with others. This book aims to honour the narratives of contributors as important sources of knowledge capable of advancing collective understanding and empathy in communities. Contributors provide a powerful reminder of the importance of breaking down barriers and ensuring that everyone has equal access to the opportunities and services they need to thrive. By sharing narratives, we hope to shed light on important issues, promote positive change and inspire others to embrace and celebrate their diversities.

Above all, this book is a celebration of the human spirit and of the resilience and determination that enables individuals with disabilities to break down barriers and stigma. This book is a testament to strength and courage of those who refuse to be defined by ableist stereotypes, and who, instead, embrace life with passion, purpose, and pride.

Land Acknowledgement

The NWT Disabilities Council recognizes and acknowledges that its main office is located in Sǫ̀mba K'è on Chief Drygeese Territory in Treaty 8, the traditional territories and homelands of the Yellowknife Dene First Nation.

The NWT Disabilities Council recognizes and acknowledges that, by working throughout Denedeh (what is presently the Northwest Territories), we work within many traditional territories of First Nations, Inuit, and Métis peoples whose rich cultures, histories, and languages continue to shape this land. We also recognize that this land is governed by historic treaties and modern treaties and land claims agreements, and that all people have a role to play in upholding the spirit of these agreements and advancing Indigenous self-determination.

The NWT Disabilities Council recognizes the physical, emotional, and spiritual violence inflicted on First Nations, Inuit and Métis peoples since European contact through colonial projects of assimilation and erasure. We recognize that the ongoing legacy of colonialism continues to result in the disproportionate experience of, among other things, physical and mental disability in Indigenous communities. We recognize that disability justice in the Northwest Territories requires decolonization.

McLeod Family AKLAVIK

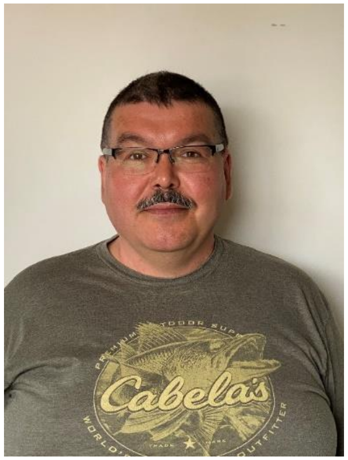
"Being included means being able to live a full life with family and friends in our home community."

My name is Deanna McLeod. I am 25 years old, and I have lived in Aklavik with my parents and the rest of my big family all my life. I love living in Aklavik and being close to my family and friends. Some of my favourite things to do in Aklavik are going to community events like festivals and feasts, skidooing, camping, boating, and working on my physio.

Although I have always lived in Aklavik, my life here hasn't always been the same. My life started to change in 2010, when I had a seizure in junior high and had to be medically evacuated down south for treatment. After some time down south, I was able to come back to Aklavik, but I had new challenges to adapt to because of my medical condition. I was able to adapt to my new needs and continue living with my family and going to school until 2014, when I had a much more serious and scarier neurological event. I was medically evacuated down south again, but this time I was in a coma for four and a half months. After I got out of my coma, I had to stay in Edmonton to work on my rehabilitation for another four months before I could return home to Aklavik.

My journey in coming back to Aklavik and adapting to life as someone who is blind, partially paralyzed, and in a wheelchair, hasn't always been easy for me. One thing that has always gotten me through is my family and especially my parents. They have always supported me and helped make sure that I have the best life I can. I wanted to participate in this project to share my story, to show the importance of living in my community, and to raise awareness of the supports that help me live a full life.

My name is Anna Lee McLeod. I am a mother, grandmother, wife, and Gwich'in language teacher here in Aklavik. I am a mother to Deanna, as well as my three sons, Jordan, Brandon, and Kayden. I am also a proud grandmother to ten beautiful grandchildren. I am proud to be from Aklavik, which is a strong and close-knit community. It is important to me that my family is able to live here together, and that Deanna is able to live here with us. When our own people from our communities are put into southern facilities, they can go into depression because they don't have familiar places, culture, or family and friends to be there for them. I never wanted that to happen to Deanna. My family works together to take care of each other and to ensure that Deanna can participate in activities that keep her mind strong. This project is important because people in the territory need to know how important it is for people with disabilities to be able to stay in their communities where they grew up, are comfortable, and have family.



My name is Dean McLeod. I am Anna Lee's husband, Deanna's father, father to our three other sons Jordan, Brandon, and Kayden, and am also a grandfather. I am the Recreation Coordinator for the Hamlet, so I organize community and cultural events. It is very important that people from our community are able to participate in social and cultural activities; it keeps us strong and helps our well-being. This is something that is very important to me and my family when caring for Deanna. We make sure that Deanna can come out to these events, and this is a big part of our lives. It was never an option for us to not bring Deanna home. While I am grateful that we could bring her back to Aklavik, I know that because of the financial barriers, not everyone in our community can do the same. I want the government and public to know how important it is to help families and support people with disabilities, especially in smaller communities. Families need support to care for their loved ones.

Coming Home to Aklavik

2014 was a really difficult year for our family. After Deanna was medically evacuated to Edmonton and in a coma, we weren't sure what would happen or what her recovery would look like. What we did know is that we had to be there with her and that we would do anything we could to help her. Anna Lee went on leave from work and put a cot in Deanna's room and slept beside her every night. Dean and Kayden were also in Edmonton supporting her. Other family members and friends would come to be that extra support during this whole process. We kept our faith and were determined to see Deanna come back home.

We were relieved when Deanna came out of her coma and could begin her rehabilitation. In the first four months, Deanna had to face a lot of obstacles, but, with her determination, she worked very hard completing intensive rehabilitation at the Glen Rose Hospital. She had so much strength then, but being in the hospital for so many months took a toll on our family. Deanna was essentially living her life in those four walls of the hospital room. While she was showing improvements day by day, she was still talking in whispers and her resolve to continue moving forward declined because she missed everyone back in Aklavik. We were confident that Deanna would heal better if we brought her home.

As the intensive rehabilitation was winding down and we were talking about discharge, Anna Lee and Dean met with Deanna's medical team. The hospital told us that they wouldn't consider discharging Deanna to come back to Aklavik with us until we could prove that our house met certain requirements, including a ramp and accessible door frames that could accommodate her wheelchair. Leaving Deanna in Edmonton was not an option for us. This meant that we had to pay for and complete renovations on our home by ourselves. To make it work, Dean flew back home to Aklavik on his own, without financial assistance, to organize the renovations. We were lucky because we had family that was able to help us get the materials trucked up from the south. Because of family, friends, and community members, the ramp was built within a week. Our family really came together to help us make it happen. It was only after we did this that we got permission to bring Deanna home.

The renovations we made for our entire home to be accessible were all things we had to pay for ourselves. We applied through Housing Programs, and we were told that we did not qualify for any financial support from the government. To make these renovations happen, we had to take out a $100,000 loan. This was a huge financial undertaking for our family, and it is something we will be dealing with for a long time, but we were grateful to even be able to access a loan like this. We don't think it's right that any families should be put in this position. It's heartbreaking how many people have to leave their family members with disabilities down south because of the financial barriers. A lot of these families are probably just as determined and dedicated as ours, but it all comes down to money getting in the way for them. We think it would be better for the government to provide funding to all communities to pay for the things families need for their homes accessible, rather than give money to facilities in the south where our loved ones are forced to live away from us.

Life in Aklavik

"I just enjoy being here in Aklavik. This is where I grew up. I used to run the streets of Aklavik, and I love being here. I love my family and I just want to be part of their lives."

Deanna

Since coming home to Aklavik, our family is much better off, and Deanna is much happier and healing better. Deanna is much stronger here; her vocal cords are stronger, and she speaks much louder and more confidently. We were told a one point that Deanna's speech would be affected because of the tube she had in her throat, but our Deanna proved them wrong! She is able to participate in many activities here and we take her out whenever we can. This makes our lives fuller and happier.

The renovations we made to our home have made a huge difference in our lives and Deanna is much more independent because of them. Before the renovations, Deanna was fully dependent on us for most things she needed to do within the house, which gave her less privacy and independence, and made it more challenging for Anna Lee and Dean to leave the house. Thanks to the railings on the walls and wider spaces in our living area and washroom, Deanna no longer has to call us to move around or do personal care. Funding for renovations is really an investment that keeps out people with disabilities in our communities and living better lives than we would in southern facilities that are more expensive in the long run.

Another support that has been very valuable to our family is respite. Respite services allow Deanna's primary caregivers to have a break and for her to spend time with someone who knows her disability and needs. During respite, Deanna gets to socialize and do activities that she enjoys with people other than her parents. When respite first started in our community, it was supposed to be for families supporting a child with a disability. When Deanna turned nineteen years old, her access to respite became uncertain and this was difficult. Fortunately, however, we have been able to keep our respite services going and this is a great benefit to all of us.

Having activities for Deanna to do has made her life better, but this is an area where more resources would benefit us. Deanna participates is most community events, including on-the-land activities, but these don't happen every day. We also spend lots of time with Deanna in the evenings and on the weekends, but it is difficult for us to fill Deanna's day with activities outside of the house while Anna Lee and Dean are at work. A few years ago, Deanna used to go to the college here in Aklavik on a regular basis, around three days a week. There was this local retired teacher that was hired at the College for a few months that was able to put together a program for her. It was something Deanna looked forward to and got her out of the house and kept her mind strong. However, when this person completed her term of employment a couple of years ago, there was no one who was able to step in and do this with Deanna. Communities like ours need more structured programs available during the day where people with disabilities could go to learn and do activities that are meaningful to them.

Even with the challenges, we love our life here in Aklavik. We are close with the community and our family. We love living in a place where people will pull over to offer help to get Deanna into a vehicle, where people will show up to give us rides when we need them, and where people came together to help us build our ramp to bring Deanna home. People here in the Beaufort Delta know Deanna and her story and are welcoming to her when we are out in the community. This is the best place for Deanna and our family to live.

Advice

Based on our experiences, we want to share the following advice with other families who might be going through an experience like ours.

"At the beginning, even when I wanted to come home, I was scared that once I got there, I would have more days where I was down and wasn't happy with my life. But now that I am home, I can say that there are many more up days than down ones. I have a happy life."

Deanna McLeod

"Never be discouraged about not being where you think you need to be in life. Lean on your family and friends, and don't be afraid to ask for help—that is what your community is for. And have faith, that has held us through everything."

Anna Lee McLeod

"At first I was scared to do things with Deanna because of her needs. I didn't want something bad to happen to her. Over time, I realized that Deanna is still the same person she was, she just has a disability now. People with disabilities shouldn't be treated any different than other people, they should still be able to do things they love and participate like everyone else.
I would also say to keep going and not give up. There's not all the help that you need out there, but there is some, and you can make it through."

Dean McLeod

Breanne and Adelyn Walterhouse YELLOWKNIFE

"Inclusion means that everybody has the same opportunity, but I'm not sure that they do. We were lucky getting to know the right people for Addy to be successful, but I know not everybody knows about and has access to these support systems."

My name is Breanne Walterhouse, and I am Adelyn's (Addy) mom. Addy is five years old, and currently goes to school, which she very much loves. She is super social, and school has been really great for her. She also went to YK Playschool last year, which was also good, as it let her be around other kids. Addy has two older sisters and one younger brother. She loves to be doing whatever her sisters are doing, and right now she likes to build towers with blocks both at home and on the light table at school, which she also does with her friends, which is nice. She loves to read books, loves swimming, and is doing Dance Play right now. She also likes any kind of movement; she does all the actions and dances along with Cocomelon and likes to try and tell her little baby brother what he should be doing. She likes drums and banging things together, and now that she's more mobile she likes to climb at the playground. I would like to share my story because it's always easier for other people if they hear about somebody else's experiences.

When I was pregnant, I found out on our twenty-week ultrasound that Addy had developed a heart defect, and that around 60% of kids with said defect also have Downs Syndrome. The clinic wanted to know if my husband (Tim) and I wanted to find out if Addy did in fact have Downs Syndrome. Tim and I decided that we would find out, just so that we could get prepared. We later learned that Addy did in fact have Downs Syndrome, but I think we were more concerned about the heart defect, as we knew we could figure out the Downs Syndrome as we went. Even before Addy was born, the cardiologist told us that this heart defect wasn't as severe as it could be, and they really weren't concerned that she wouldn't develop normally. Even though she would have to have surgery before she was six months old, they didn't expect there to be any complications.

The doctors wanted Addy to be born in Edmonton in case of any complications. This was very inconvenient, but, fortunately, I work for the government, so we had additional health benefits that allowed us to stay in an Airbnb and covered our travel expenses. I know this isn't an option for many non-government workers and that others who live in Yellowknife would have to stay at the Boarding Home with limited support, which really isn't feasible, especially for those who have a family to look after. We are very grateful to have delivered in Edmonton because they have a Downs Syndrome Clinic with a doctor and a nurse dedicated to the program. If any baby is born with Downs Syndrome, the nurse from the clinic comes to see you in the hospital. The nurse and the doctor are there to answer any questions you have and to give you support. This made a huge difference to us. Imagine that you didn't know your baby had Downs Syndrome until they were born. We don't have that in Yellowknife, so if you have a baby with Downs Syndrome up here, there isn't anybody coming to help you with what to expect.

In general, the message we got was vague about how Addy might be post- surgery. The surgeon said that kids with Downs Syndrome generally take longer to recover after surgery, but the doctor at the Downs Syndrome Clinic in Edmonton had the exact opposite thing to say because kids with Downs Syndrome recover generally very well after the surgery. We were also having trouble bottle-feeding Addy and the nurse at the Downs Syndrome clinic told us that was common for kids with Downs Syndrome. The Downs Syndrome clinic also had lots of good information when Addy finally came home. When Addy came home, she had pulmonary hypertension and had to be on oxygen. The doctor in Edmonton couldn't give us a specific timeline to know how long she'd be reliant on it. We were told it could be for years, but after emailing the Downs Syndrome clinic, they predicted Addy would be off all medication and oxygen within six months, and that's exactly what happened. If everybody who had a baby with Downs Syndrome was referred to Edmonton to the Downs Syndrome Clinic, it would be so beneficial. I think that every kid with Downs Syndrome should be referred down south.

I have a friend who gave birth to a little girl with Downs Syndrome, and she didn't know about the Edmonton clinic at all! I think that if you have a baby that has medical issues, you should, at the very least, be given some kind of information package or something to help, rather than having parents flying blind and struggling to find help. Because the Downs Syndrome community in Yellowknife is so small, I'm pretty sure parents of kids with Downs Syndrome would appreciate some form of support group. I would be more than happy to go talk to them in the hospital, or at home afterwards, and share whatever information I have, but we don't have a program for this.

To me, inclusion means that everybody has the same opportunity, but I'm not sure that they do. If parents were informed about getting involved with community organizations like the NWT Disabilities Council or being part of a parental support group, it would be amazing, because it can be very scary to navigate on your own. With the proper connections, parents can know everything is going to be okay and that support and respite programs are there. Early intervention has been great for Addy because she started when she was two and had someone there to learn sign language with her. So even though it took her a while to speak, she was always able to communicate, and that was super helpful.

Because of the constant support we've received, the transition to school hasn't been a big deal at all! She loves school and her communication has come so far to where she's talking now. She's also walking and running now. Her Early Interventionist also came to Physio, Speech and OT appointments with us, so they could independently work with her on these goals afterwards. All the people I feel like you're supposed to see, we were fortunately connected with. With the proper support, our experience with Addy has not been difficult and I hope that other families can experience the same.

Adam Lakusta HAY RIVER

"My personal belief is that the term "inclusion" means not to actively or passively be excluded. In the sense of having a disability, inclusion often means having a level playing field and the ability to participate in an environment of fairness. Being included is important due to its direct impact on representation."

My name is Adam Lakusta, and I am from Hay River, Northwest Territories. I moved to Hay River in 2002 at the age of ten and spent my formative years growing up in the North. I lived in Hay River continuously until 2011, when I moved south to attend post-secondary school. I returned to work each summer during my undergraduate degree from 2011 to 2015 and most of my family still lives there.

I would describe myself as a fun-loving young adult that enjoys visiting with friends, family, and outdoor activities. Aside from outdoor activities, I enjoy reading, writing, and playing games. The activities I like most about Hay River are going kayaking, walking on the beach, skipping rocks on the Hay River, and seeing my old friends and family. These things are important to me because they are integral to who I am and remind me of growing up in the North.

Following my first neurosurgery in 2016, I was diagnosed with a cognitive impairment that affected my ability to speak. This cognitive impairment caused me to hear about the Northwest Territories Disabilities Council (NWTDC) and their Learning Supports for Persons with Disabilities (LSPD) program. The NWTDC and the LSPD program have provided invaluable supports for myself and my family.

What I want others to know about my disability is that my impairment hasn't changed who I am. I am still the same Adam as before the surgery; however, I have had to develop different skillsets to speak. It is difficult to separate my disability from my brain tumour diagnosis. My disability has impacted my life in the sense that I can no longer do things with the same disregard to details. What formerly were engrained skills that I could take for granted when completing tasks, I now have to pause and review. Another way that the disability and diagnosis have impacted my life is psychologically. For example, I will often do a task and wonder whether it would have been easier to achieve before my surgery.

When asked how living in Hay River with a disability was, I can only comment in general terms. When I was told I had a cognitive impairment, I was living down south for post-secondary school. Nevertheless, as my fellow Northerners and Hay Riverites found out about my diagnosis and disability, everyone was very supportive and understanding. I have never been treated differently in Hay River because of my impairment. The North can be a difficult place to live and grow up; because of this, I believe that Northerners are patient and understanding of individual differences.

Regarding my work experiences, I have worked in a variety of positions. My first job was working at the Riverview Cineplex in Hay River beginning when I was 12. From there, I worked many different summer positions until completing my degrees. Generally speaking, my experience is that working from a young age has better prepared me for school, the workforce and volunteering. Things that helped me as I worked in different positions were my work ethic and my desire to leave things better than how I found them.

In terms of my relationship with my disability and diagnosis, these views have changed as I've developed skills and have come to terms with my life following the surgery. When I was first diagnosed with a disability, I tried to ignore it and live my life the way I used to. It took a couple of years to realize that this tactic wasn't working, and I needed to embrace the programming and accommodation that was available to me. Once I was willing to accept that life was going to be different, I began exceling and feeling less stressed and disappointed in myself.

Most of these experiences related primarily to school. Following my diagnosis, experiences I had in university were largely positive. I found that people either knew I had a disability and were sympathetic to it, or simply didn't notice. I received some accommodations for tests and assignments, however, I always challenged myself to limit my use of the accommodations to the extent that I needed them.

Despite mostly having positive experiences in school, issues that made school more difficult mostly related to the format of exams. For example, certain instructors would intentionally design their tests to require the whole time to complete. Whereas I did require accommodations, I felt as though I may have had an unfair advantage taking extra time, when I knew that these exams were designed to be a time crunch. This exam format made it difficult to gauge whether my difficulties were the same or different from others in the class.

I intend to use my work ethic to achieve my personal career goals, which include becoming a great intellectual property lawyer and patent agent working in the life sciences. In terms of volunteering, I hope to continue expanding my volunteer efforts and contributing to causes where I can add value.

The response I get when people learn I have a disability tends to be muted and often followed by amazement. The reason I believe I get this response is because, up until that point, they never would have thought I had any impairment. Once they find out and begin asking questions, they realize the issues I have had to overcome in getting where I am today. I would say that the response hasn't really impacted me, although it is a topic that I am always willing to discuss openly.

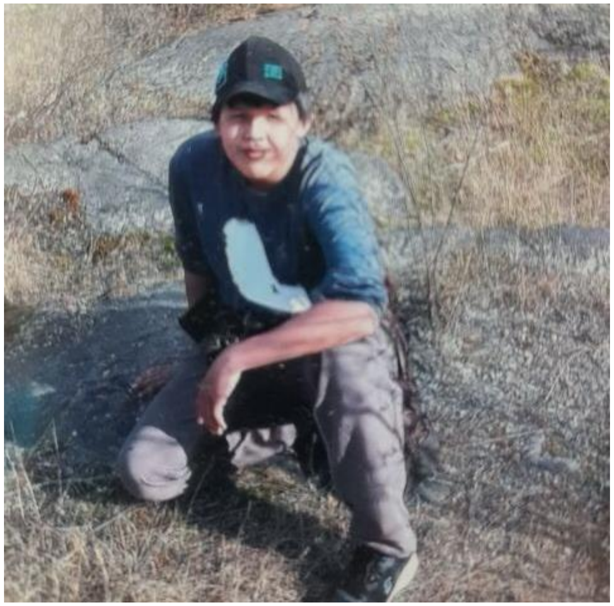
For the most part, the people in my life have been very supportive once they learn about my diagnosis and disability. In general, however, the one thing I would like for people to stop thinking is that people are somehow faking their disability to get advantages. This topic came up over and over again amongst my colleagues as I attended school. There are medical professionals and institutions in place to assess and diagnose disabilities. To question the legitimacy and character of an individual's diagnosis is also to question the medical professionals and institutions involved with the diagnosis. Although there *are certainly individuals faking their diagnosis to obtain advantages, there should be a strong presumption that a diagnosis is correct, and any investigations should be left to the professionals and not the subject of speculation.*

My life has been improved by being open about discussing my diagnosis and impairment as well as accepting accommodations. Advice I would give to others is to accept your disability, do what you can to overcome aspects of it (whether they be physical, psychological or both) and accept help where you need it. People often feel a sense of powerlessness in the face of disabilities, so they are usually willing to help.

My personal belief is that the term "inclusion" means not to actively or passively be excluded. In the sense of having a disability, inclusion often means having a level playing field and the ability to participate in an environment of fairness. Being included is important due to its direct impact on representation. Whether it is education, politics, or recreation, if barriers exist blocking participation for certain members of the population, then the voices of those members will not be heard. Society requires everyone to have an equal opportunity to be included so that it can continue to improve for future generations.

Hilda Football YELLOWKNIFE

"Living in Yellowknife as a mother of children with disabilities you see the difference in opportunities. In Behchoko there's nothing to help people. There's a lot of single mothers with four or five kids and it touches my heart because I really want to help them."



My name is Hilda Football. I am originally from Behchoko, but I've lived in Yellowknife for five years now. I am a mom and grandmother. I have two sons, both of whom have disabilities. My youngest son, Jay, has autism spectrum disorder and my oldest son, Kevon, is diagnosed with global and developmental delays. When I say that Jay has autism, it's sometimes hard to explain because autism can mean so many different things and looks so different on everyone that has it. I focus on telling them about how Jay is. My son Jay is really smart and uses his manners. He's also a really funny boy.

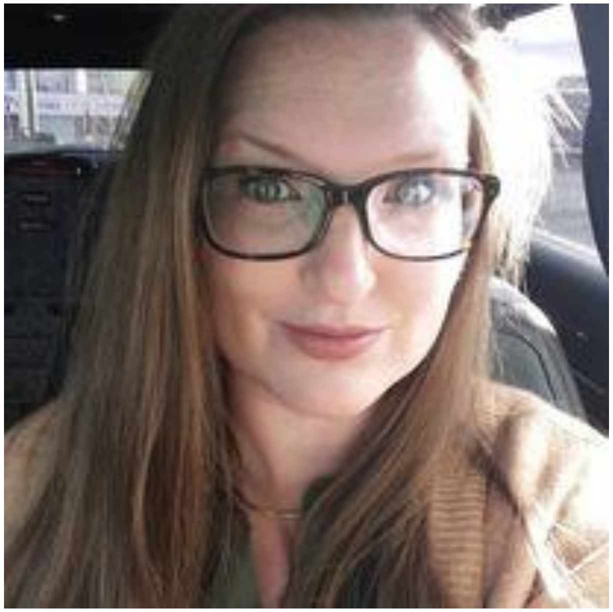
My sons' disabilities impact them differently and I do my best to learn about what they need and help them. For my son, Jay, I put a lot of effort into making sure that he has a regular routine because this makes his day easier. I also listen to the advice of our doctor that he needs to get lots of exercise for his hyperactivity and to work on walking because right now he moves around on his tiptoes. I make sure he has an active life and stays busy. For my son, Kevon, I take extra time when I give him instructions to make sure he understands. With Kevon, I often repeat myself because he tends to ask lots of questions. For example, if I ask him to shower, I'll have to say it lots of times, and then he'll come back with questions about what soap or shampoo to use. This means things take longer for us. Right now, Kevon also is having a harder time with learning the alphabet, so I take extra time with him with flashcards that I post on the wall in our house to help teach him. I also help correct him if he makes mistakes and help him pronounce the different letters. Kevon recently got a hearing aid, which has helped him hear the different letters better. Even though he has a hearing aid now, we know he will be deaf in the future, which is going to be a big change. We try to teach him as much as we can now so he will be ready. I go online often to take training because I want to learn as much as I can about both of my sons' disabilities and to learn new skills.

Kevon started school in Behchoko when he was only three or four, and I had a hard time with him because he was at school having challenging behaviors, and I had to leave work to go in and see the teacher all the time. I took Kevon to the doctor, and he was able to give a diagnosis. Since the father wasn't helping, I'd have to leave work and take him home because *they couldn't deal with him. I was also going through a rough time in my relationship, and I moved to my mom's house. It was then that someone told me that the YWCA had emergency units to live in, so that's when we moved to Yellowknife. I learned that there were lots of opportunities in Yellowknife compared to Behchoko and I started taking Jay to speech specialists and doctor appointments. That is how we ended up learning more about his disability. Jay also was accepted into early intervention with the NWT Disabilities Council, so he was able to attend Montessori School with a one-on-one worker. At first, I was scared when he started school because I was nervous that he'd have the same experience that Kevon did; however, I quickly saw that our intervention worker was nice and able to help him a lot.*

In the first couple of months of moving to Yellowknife, I had a hard time with Kevon at the new school. We went to Speech and OT appointments and Kevon hot assessed by the doctor. It was there I was referred to the NWT Disabilities Council, and they helped me get Kevon more support. Now Kevon has an educational assistant in the high school, which really helps. There have been no more emotional breakdowns with Kevon since we got all the support here. There's also lots of centres in Yellowknife that help me, like YWCA. Living in Yellowknife as a mother of children with disabilities you see the difference in opportunities. In Behchoko there's nothing to help parents with children that have needs like Jay or Kevon. There's a lot of single mothers with four or five kids, so it touches my heart because I really want to help them. In Yellowknife, there is a lot more support for kids with disabilities that can really help.

An ideal life in Yellowknife would look like getting my kids in more after-school programs, especially for Kevon with tutoring for reading. It would be good to have these kinds of programs for kids and youth with disabilities. I also wish there were support groups for single mothers of kids with disabilities in Yellowknife and Behchoko so we can share our stories, ask questions, and learn together.

Once Kevon finishes high school, I want to get him more help for things like summer school and other educational programs. I'm trying to find other things like that, which will help him to keep learning after he graduates. He has said he wants to be a security guard or a cop, so I tell him he needs to keep learning and working at school so he can do that one day. I don't really have a lot of fears about my boys' futures because I know I'll be there for them. I don't know where we're going to be next year, but I stay strong for them. I want to be able to provide a safe home for them to live and grow.



Nicole Sok YELLOWKNIFE

“It's one thing to know that maybe you're different, it's another thing to know that your difference doesn't stop you from being seen, heard, loved, and valued.”

I am Nicole Sok, mother of Caleb Sok, and we live in Yellowknife. Caleb is a very smart boy, and a lot of people are actually surprised he has a diagnosis, and some don't even believe it! Some days, I have the patience to explain that he is autistic, what his challenges are, and the things that make him super awesome, and sometimes it feels pointless dismantling the stereotype.

I want to take part in this project because I thought it would be beneficial to hear other people’s voices on the subject of autism. Autism is a spectrum, and I know that even within Yellowknife there's quite a lot of diversity amongst how autism presents itself. I thought another voice giving a different side to this disorder would be helpful, especially since my son didn't present the stereotypical characteristics of autism that others looked for.

As a young child, Caleb was minimally verbal and had his own language, which made it very hard for others to understand him. This led to a lot of frustration, especially when he thought he was saying the words you were repeating back to him. He would get very upset that people couldn’t understand him and would lash out. It was quite common for his frustration to manifest in a destructive manner.

Caleb was later diagnosed with a language disorder and autism that is considered on "severe" side of the spectrum, which, to be honest, really doesn't explain much. However, it wasn’t easy to get a diagnosis. We were told by Glenrose that a lot of people would not give him the help he needs, because they wouldn’t be able to see which areas of his life that he needs help with. They were very thankful, however, that I was able to catch the things I did, and that I was persistent, because a lot of trained staff were sceptical of whether he would get a diagnosis— that’s the difference between living with somebody and seeing someone for a snapshot in time.

At school, Caleb was expected to be ‘on’ for six hours a day. When he came home, he would have what the paediatrician described as “Nuclear Hour,” where there aren’t as many expectations on his behaviour. School was draining for him, and it was very hard for our family. There was a lot of screaming, throwing things, and since I was his security blanket, it essentially left me unable to perform my other evening duties.

Now that he is home-schooled, life is drastically different. There's not such a major swing in his mood during the day, so now he has better relationships with his siblings and parents. There are fewer challenging behaviours, and I'm able to tailor his education in a way that suits him better. I can motivate him using the things I know he loves, give him the breaks he needs, or help him if he's just having an off day. His days are a lot better now; I think a lot of people could run into him now and go, "oh I didn't know he was autistic". This is because his day-to-day interactions and schedule is very balanced and nuanced; his cup isn't overflowing all the time, which decreases the possibility of Caleb becoming upset, and his sensory needs are met consistently.

Having gotten the formal diagnosis, I wonder what Caleb's life would look like if I had not really pushed for that assessment; it was a really big tool to have very early in his crucial, formative years. Thanks to his diagnosis, we could see Caleb's progress and where he was still developmentally behind more easily. We knew what his challenges were, but, because of the diagnosis, we had the building blocks to get him to where he is today. He still has an evident language disorder, but he can communicate and hold conversations with you now. A lot of people are quite able to understand Caleb now because speech therapy has really helped. Being able to follow along and then putting what was learned into practice at home helped me as much as it helped Caleb.

When Caleb first entered preschool, he had a teacher that didn't understand autism and her frustrations were noticeable, so, due to her rigidness to making accommodations for Caleb, we ended up medicating him for a year. Caleb did much better when he had an educational assistant. The educational assistant gave him somebody to advocate for him. Having an advocate in the class that was one-on-one with Caleb was great. This support took the burden off the teacher and gave Caleb a safe space and healthy ways to get help when he was stressed or overwhelmed. Having that assistance when he was first learning the 'rules' of school and socially acceptable behaviour set the foundation for him to do well on his own-especially since he ended up losing that one-on-one support later in Junior Kindergarten. It was good for him being in a space where he learned how to socialize with children beyond his siblings. Watching and observing his friends helped him a lot in his formative years. He learned to wait and to play, and focusing on what the teacher says. When Caleb was very little, he also took part in the Special Olympics, and I was grateful for that. It was a safe space to learn how to play fairly with others, practice hand-eye coordination, motor function, and other skills.

I am grateful that services like speech therapy and occupational therapy are provided by the GNWT. We're not paying out of pocket for these supports like in other places around the country, which can cause families to barely keep their heads above water financially. I'm thankful that's available, because other than those therapy supports, I don't think there's really anything for kids with disabilities privately. However, since Yellowknife is the largest urban centre in the Northwest Territories, families often end up leaving communities to get the support they need. The services that are offered here are stretched too thin and the supports we do have are triaged, which means we have to look at who needs help the most right now. Once you're in the program, you're generally not in them for very long, or not getting the level of service you should be. Studies show that occupational and speech therapy services are most effective when they are done weekly, which is often not the case here. Government thinking is very short-term, so it's sadly not an uncommon problem. We need to invest in our children, youth, and adults with disabilities because the return on that investment is massive in the long run.

Inclusion means Caleb can have a healthy self-esteem. Inclusion means that that his disability doesn't impede him. For him to be included, or for him to be able to participate in things, bolsters his self-esteem. It's one thing to know that maybe you're different, it's another thing to know that your difference doesn't stop you from being seen, heard, loved, and valued. The only fear I do have about Caleb is more in regards to his future. I know he wants to be in the military and my fear is that his diagnosis will keep him from pursuing his dream. We have ten years to change that.

We have a society that works best for a certain group of people and if you don't fall within that group, you are more likely to experience poverty, unemployment/underemployment, and to be less educated. However, I do know incredibly intelligent people that got into university even though they weren't able to get the support they needed to be successful. Corporations are also not structured around disabilities. When we take the time to address and see people for who they really are and what they're actually capable of, it just goes to enrich the world and society. I kind of like the saying that "if we were all the same, one of us would be irrelevant." I think that goes for disabilities as well; just because somebody has a disability, it doesn't mean that they don't have amazing things to offer society in ways that we would maybe never think of.

My advice is to never give up on your child and their future—don't allow yourself to believe that how things are now will be as good as it's ever going to be. Your kiddo needs to know you believe that they are capable of having the future they desire. I know when doctors are talking about childhood vaccinations, they say, "Don't worry, it doesn't cause autism." It's as if there's this weird connotation that if you're autistic you can't live a full life, be happy, or have goals and aspirations that you want to reach. I see no reason that those things should be out of reach for Caleb so long as he has the appropriate long-lasting supports that he needs to achieve what he wants.

Grace Shed and Wyatt Cameron BEHCHOKO

"I think being included is not just being only invited to situations, but people actually going and thinking through their plans for an event so everyone is thought of.'"

My name is Rebecca Gracie Cameron, and I am from Behchoko. I have lived here off and on for the last 30 years. My son, Wyatt, is eight years old and an incredible force of nature. He is intelligent, loving, and adventurous. The thing that makes Wyatt happiest in his day-to-day life is his dog, who he has a strong connection with. Although Wyatt is empathetic in his life generally, it shows the most when he interacts with our dog; when they are together, he is very affectionate and communicative, it is a beautiful relationship that makes his life better. He also has his little gadgets and technology devices that he enjoys, like his tablet. Wyatt uses his tablet both for entertainment and for learning. He loves discovering new things from the videos he watches and trying to communicate what he's learned.

I think it's great to have other people ask questions about disabilities because there's no way you could possibly know what somebody is all about without asking. I'm always on board for answering anyone's questions about what it's like to live with Wyatt and what he needs in his life. My son has severe non-verbal autism and also has a lot of needs that make him different than other children his own age. Wyatt's disability means that noises, people, and different situations can all upset him, which means that parenting him takes a lot of work. I think that we can focus a lot on the negative aspects of disability, because they can overwhelm our everyday life, but I want people to know that there are so many positives as well. Wyatt's disability doesn't take away from him as a person; he is an incredible human being, who we are lucky to have in our lives. Wyatt is inquisitive, lighthearted, and a real joy to be around.
Wyatt is hit-and-miss at school, but he's got an amazing teachers and aides in the school programs that try very hard to understand him. It's inconsistent, however, because a lot of aides get worn out and end up moving on very quickly, meaning that Wyatt can go through as many as three or four aides in a single school year. The inconsistency for him is very difficult. The aides have stayed and the teachers that have put in the extra effort for him are incredible and have developed ways to improve his learning and help him get through the day. I think that it would be extremely beneficial if we could have a program in place that could help educate teachers on how to help a child like Wyatt learn. Wyatt is intelligent and I see the potential, but being able to teach him in the way he learns is so different and is not something that can happen in the average classroom.

Living in Behchoko with a child with a disability is also very challenging because there are very little resources open to children with disabilities in the communities. There are no resources available like after-school programs or sport programs of any kind. If I could do it my way, respite would be available in the community for all the parents of children with special needs. There would be programs available, like special needs soccer, volleyball, or any other sports. I think this would be beneficial because *there's actually a significant number of children in the community with special needs who do not have activities to do. I also think it would be helpful to have an organization for the parents in this town to spend time talking and sharing our stories and our children with each other.*

The fact that the communities in the north are so small does allow for everyone in the community to get to know everyone else, so people know who Wyatt is when he goes out. This is good because it means we are less likely to meet ignorance or offensiveness when Wyatt misbehaves or acts a certain way in public. People here usually don't look and go, "What's wrong with that eight-year-old?" or "Why is he behaving that way?" because they know who Wyatt is, which is nice. Wyatt also loves to go to the different playgrounds in the town, and, being in a such a small community, it is nice because all the kids there go play with him the way that he plays, even though it is very different than an average child. The kids here know who Wyatt is and they just automatically know he'll play in his own way, but they still involve him.

In the community, I think most people look and genuinely just go, "Oh that's difficult for you." There is a sense of affection, almost like they appreciate that it's hard for you and they try to make room for that. At the same time, a lot of people don't have room in their own lives for anything that's out of the norm and that makes things more difficult for them. I think people try to be understanding, but only so long as it doesn't affect them in any way. It's like if we're going to hang out and your child is going to be a problem in 90% of the situations that we spend time together, it's easier just not to invite you or have you around. A lot of people don't have the ability to make room for more difficulty in their own lives, so it does make it more of a challenge for us to build friendships.

Another thing that is difficult to deal with is that some people absolutely believe that Wyatt's condition is caused by some kind of negative action on my part, like vaccinations, drinking caffeine, or a number of other myths. I've heard that some people believe that autism can be caused by mothers not being affectionate enough towards their children. These people act like someone is to blame for Wyatt's condition, instead of just realizing that this is just part of who Wyatt is. There's also the belief that if someone has autism, they must have some kind of superpowers or special abilities, for example with numbers or patterns. This is portrayed in movies like Rain Man or The Accountant. In reality, people with autism aren't like these stereotypes, and Wyatt is special the way he is. Wyatt doesn't have to be a superhero or have a superhuman ability for him to have a valid reason to be here, he just is and that's his reason.

I think every parent with a child with a disability has major fears. We fear he won't be happy. We fear that we will fail to get him as far along in his development as we can. We fear that one day, when we die, there's going to be no one left for him to depend on and he'll be in a system that might fail him. We fear we won't live long enough to take care of him and give him the life we want him to have. We also fear all the time that something could happen and he could get hurt, or killed, especially when you have a nonverbal child who can't communicate. But as parents, I think one of the greatest fears is how are we going to take care of him when we're eighty? How are we going to take care of him when we are gone? That's something that motivates every decision we make.

The support that Wyatt has received improves his day-to-day life and has made our lives much better. The occupational therapy, speech therapy, and all the intervention programs that he has done since he was a baby have improved his tolerance and ability to handle social situations longer, which has improved our family's life quality. These supports have helped us go from us being completely isolated to having the ability to take him out in the community for longer periods of time because we now have the tools to help teach him how to cope in these situations.

I think being included is not just being only invited to situations, but people actually going and thinking through their plans for an event so everyone is thought of. I know that this requires extra effort on someone else's part, but this would make our family feel so much more seen and included. Our family has a lot to offer people and we are always so happy and grateful to be in situations with other people, since it is often too difficult for us to attend. Having our family around more would help people see that getting to know someone like Wyatt is a benefit to everyone in our community. I'd like our family get to know more people in our community, as I think that there's so many amazing people out there that we're missing out on.

My advice for those who have children with disabilities is just to love the child you were given. If you need, you can grieve the child you thought you'd have, but it's important to start finding ways to relate to this new human being who will lighten up your life in so many ways. Ask for help and know that you're not alone. Know it's okay to cry, or get upset, or say that this is too hard, because it is too hard… it's inhumanly hard, but it's also an amazing experience—it can be both things! Don't cut yourself off because there are people out there who understand and would be happy to talk to you. Every person who has a loved one with a disability has a million things they want to share with you about their child and about their life. If you know anyone who is in that situation, I say you should feel free to ask them to just tell you anything they want to tell you. I guarantee you'll probably be sitting there for an hour or two as they gush about their life and their family. You will probably walk away with more information than you ever thought.

Stephanie Williams YELLOWKNIFE

“Inclusion means an environment where everyone, despite their race, gender, sexual orientation, and abilities are included and are given an opportunity to thrive and succeed.”

My name is Stephanie Williams. I was born and raised in Toronto, Ontario and I moved to Yellowknife in December 2010. Right now, I am 41 years old, and I've always known, or had a feeling, that I have a learning disability. But growing up in school, I wasn't sure what type of learning disability I had, I just knew that it impacted my reading and writing. I didn't get diagnosed with dyslexia until 2019, at the age of 38. The diagnosis completely changed my life and has helped me to understand why I struggled so much in school when I was younger. I want to share my experience.

When I was still in school, my parents weren't aware of different resources, assessments, or supports that were available to students. As I got older, I just kind of got used to struggling. By the time I was an adult, I thought it was too late for me to find out what my challenges were. I didn't know that adults could take the time to do assessments and get a diagnosis. I thought it was more for kids that were in school and that I was just too old. The reason why I finally got the assessment that led to my diagnosis was because there was a job opportunity available to me that my supervisor wanted me to apply for. After sharing with her my concerns and fears around some of the responsibilities that would be a part of the job—like writing, reading, and editing emails and reports—I was very fearful. However, once I shared my concerns with her, we were able to talk about really trying to figure out what those challenges were and what supports would make me successful in that role.

We decided that one of the first steps was getting a formal diagnosis. That’s where everything started for me. I went through the process of contacting someone that would be able to do that assessment on an adult, and, after going through that, it was confirmed that I had dyslexia. That diagnosis highlighted the different areas of weaknesses and strengths I have, and it clearly outlined different modifications that would be helpful for me is a school and work environment.

Some of the ways that having a disability impacted me growing up in school was difficulties with completing work, understanding work, and working extremely long on assignments and projects with little payoff. I realized that the work my peers did overnight always got like 90%, when it took me a week to complete the same project, only to get like 50%. This was due to grammar, spelling errors, and just being unable to translate what was in my mind onto paper. It always impacted the quality of work that I was able to do, which in turn affected my self-esteem and self-worth.

I found that the school system was not prepared to properly support someone like me. Often, I found that they just pushed me along, they didn’t complete the proper assessments or communicate with my parents about what was going on or what my challenges were. Being a child of two immigrants, my parents were not aware of different disabilities or how to properly support *children with disabilities. I was left to just kind of get through the school system, hoping for the best, and develop my own coping mechanisms to help me get through the best way you could.*

One of the biggest challenges that you face living with a learning disability is that often people think less of you. When you make errors, or you're not able to articulate yourself quickly or fast enough, you're viewed as not being intelligent. Sometimes you can sense people's attitudes or judgment towards you. Knowing that you tried your best and that there will always be people that will see your mistakes as lazy, negligent, or just messy, is hard to deal with on a day-to-day basis. Being older now, one of the things I think about most being in Yellowknife are the children in the school system that might have undiagnosed disabilities. These undiagnosed disabilities can impact their experiences at school, it can impact the quality of work that they are able to produce, their ability to understand what's going on in the class, or their interaction with their peers. I worry about them because I know how difficult it was not having the proper resources or supports. I know that in Yellowknife a lot of people are not getting diagnosed and there's not enough resources available for children, youth, and adults that are living with a learning disability to help them be successful.

I think now that I'm older, I can see how being person of colour, as a black woman, was a factor in how I was treated in the school system. When I look back, I can see how my non-racialized counterparts with the same disability, or similar challenges were able to receive additional support while my siblings and I, who all had varying degrees of learning disabilities, were just pushed through the system. I feel like we were written off by the school system because of where we came from in the city and the colour of our skin. I can recall one of my brother's teachers telling my mom that she might as well keep him home because he'll just end up being a garbage-picker. Later on, we found out that this brother had a learning disability and ADHD. They did not support him. They would often put him in the hall to sit and do work on his own, which caused him to miss out on a lot of lessons and fall further behind. I can see how the school system was systemically racist when I think about this treatment and the overall quality of education my siblings and I received as black children.

As I have gone through this journey, I think the most life-changing thing for me was finally having someone believe in me. When I came to my supervisor with my concerns about reading and writing, I was met with encouragement, which opened doors that I would not have attempted to walk through on my own. Being able to get the resources I need to learn about myself and my challenges has changed my life completely; it has given me confidence and helped me realize that my disability doesn't make me less. I now know that my learning disability doesn't mean that I'm worthless or that I can't do things, it simply means that I just learn differently and need more time, resources, and support to help me to be the best that I can be.

Every part of my identity has and will continue to impact accessibility and inclusion. Inclusion for me does not only pertain to my disability, but it must also consider my whole self as a disabled, queer, cisgender woman of colour. An inclusive environment should be where everyone, despite their race, gender, colour, orientation, and abilities are included and are given an opportunity to thrive and succeed. Inclusion is important for me because I have experienced firsthand how the lack of inclusion can impact someone's self-esteem, self-worth, and productivity. I found there were many barriers that prevented me from learning. In an inclusive environment, I am able to flourish and experience great success. It was only in an inclusive environment that I began to see my strengths and build more self-confidence. It honestly changed my life.

Eddy, William, and Abby Finnamore YELLOWKNIFE

"I wish a lot more people were aware that disabilities can exist and that odd behaviours could actually be as a result of a disability, instead of somebody just misbehaving."

Hello, our names are Jennifer and Tim Finnamore. Jennifer has lived in Yellowknife since 2004 and I have lived here since 1993. We have three children: Eddy is ten years old; William is seven; and our youngest, Abby, is six. Eddy is currently obsessed with building camper trailers out of Lego, William loves spinning wheels on cars and reading, and Abby loves playing with her Barbies in her big Barbie house. Eddy and William both have autism, and we suspect the same for Abby. Back in 1996, when I was 12 years old, I was also diagnosed with what, at the time, was called Asperger's, which I believe now it's just referred to as high-functioning autism. I also have a comorbidity of ADHD. We want to do this project to help spread awareness and help others navigate disabilities. Our family is really different than other families. We have good days and bad days, but we wouldn't have it any other way.

I was diagnosed when I was in school. The teacher I had at the time was actually the one that got the ball rolling on the diagnosis when she said she saw something abnormal. She had experienced that with another child, so she asked the right questions and got things moving. Being diagnosed was just a bit of a relief in the fact that I finally had an explanation for my struggle, and from there I could work on mitigating my issues. It was just a relief to know that this was a thing other people are challenged by and there was a light at the end of the tunnel. I don't think my disability really matters either way, because, like the line in Shakespeare, "A rose by any other name would smell as sweet"—that's always been a line that's stuck with me.

Ours kids were diagnosed earlier than I was. To get their diagnoses, we had to go to Edmonton where a team did an assessment. After we got the diagnoses, the staff in Edmonton gave us lots of resources that identified supports, but the problem was that these were only for people in Edmonton. When we got back to Yellowknife, we really didn't know what we were supposed to do. There really isn't a lot of autism support or resources actually available up here, so it was quite an adventure, especially in the beginning. What would be helpful is to have some kind of navigator here in the territory to point you in the right direction.

All our kids have lots of energy, but we wouldn't have it any other way. Having autism isn't the end of the world; our kids are a lot of fun to be around and give you a different view of the world. Getting them to do tasks, especially ones they don't want to do, can be hard, but the secret is not to worry about it and to just give yourself extra time to do things.

In general, we find that their school is very inclusive and accommodating. I remember one day we were picking them up after school and some of Eddie's classmates were teaching him how to play on the swing. It seems like everybody knows Eddy has autism and accepts that. The school is 100% willing to learn to help them, and I know that helps our kids be successful. I know the school consults with an autism team in Edmonton for support and this helps. We did have a worker in the school who was great and with them for the year, but her contract wasn't renewed for some reason, which was very unfortunate. Having that one-on-one support, that accommodation, is going to be critical for them as they age. Later, I see maybe needing some more specific assistance around some of the challenges with puberty. One-on-one support might need to be specialized, but it's the future, so it's hard to know right now.

Summers with our kids is hard because what do you do when there's no school? School is a massive help for your sanity as a parent and caregiver. School is also important to our kids because it gives them productive things to do. There are very limited placement options for summer camps when children have disabilities in Yellowknife. These children have needs and we need to send them with one-on-one workers, but there's only so many workers and camps available. On top of that, the camps are expensive. Similarly, during the COVID shut down, doing school from home was so hard because they were all on a separate IEPs (Individual Education Plans) than the other kids, so it was basically just a big break for them.

For the past five years or so, I've noticed that a lot more people are becoming aware of the fact that mental disorders are common; however, I think these people are not necessarily aware of the specifics about what these disabilities look like. I wish a lot more people were aware that disabilities can exist and that odd behaviours can actually be the result of a disability, instead of somebody just misbehaving. I have, for example, noise sensitivity, so when people start making noises, I need to put on headphones to block out the sound. Some people think it's rude, when, in reality, I'm not being rude, it's just something I need for regulation. Sometimes when someone says "hey this noise is bothering me" others will tell them just ignore the noise, but it doesn't work like that. Some of the smaller things like that can really impact people and it is easier when others are supportive and understanding.

Emily Heeringa & Bert Heeringa YELLOWKNIFE

Emily is originally from Vancouver and has lived in Yellowknife Northwest Territories for the past eight years. Bert is Emily's father who lives on Vancouver Island.

"Inclusion means understanding that people need some adaptations in order to be the best version of themselves."

Emily: I would describe myself as a kind, loving, passionate, and empathetic person, who adores her children with everything she has and will advocate for her daughters until the end of the earth. My daughter, Sophia, has autism and sensory processing disorder. I wanted to do this narrative because I want to provide a voice for those who don't have one, to help advocate and support families and individuals who have different needs, and to bring awareness to our community. I want people to know that just because someone has a disability, it doesn't impact what they can accomplish. Disability has many looks, and because someone with a disability does something in a different way, it doesn't mean they can't attain the same thing as everyone else. Disability has changed my life for the better; it has made me a more aware, empathetic, and kind individual who wants to learn, have justice, and provide awareness for others. Living in Yellowknife as a parent of a child with a disability is isolating, lonely, and overwhelming, but I want others to know they are not alone.

I think sometimes, depending on where she's at during the day, Sophia's disability is fairly obvious, and to someone with a trained eye, they can see it easily. But to the average person, Sophia is able to blend in, or mask it, so I'd say people are generally surprised to learn she has a disability, especially at a distance. I do have fears disclosing Sophia's disability; it took me a long time to acknowledge it and is still something that is hard to say sometimes, but it's not about Sophia, it's about her diagnosis and how people respond to a label. I want people to know she's a person and so much more than any label. I worry she'll be put into a certain category, when I know she's capable of achieving anything she sets her mind to. I think some people lower their expectations when they find out she has autism and underestimate her, when it should be the opposite. I think those who know her are in awe of her because she's a little girl who's been able to persevere through so much.

The thing that helped Sophia in school, hands down, was early intervention because this laid the foundation to help the teachers and the EAs learn about Sophia, her diverse needs, sensory breaks, and made an individualized education plan that allows her to learn. The challenges we have faced in school are the lack of education on her diagnoses and understanding how to support her. Another challenge is understanding the intensity of sensory breaks required and how important these breaks are to get Sophia into a space where she's able to learn.

There are things that are still hard for Sophia to engage in. What I notice the most right now is challenges with anything recreational like swimming, soccer, dance, or other activities designed for neurotypical children. There are no sort of adjustments or balances to make it so that children on the spectrum, or with diverse needs, can participate unless the parent goes one-on-one directly. In those instances, their disability ends up being highlighted because it's obvious when you're on the soccer field with your child and you're the only parent. It would be amazing for some activities would provide these children with diverse abilities extra support in an inclusive setting.

Yellowknife has just got an accessible park and it seems like the city has been gaining a lot more awareness lately. Things such as sensory Santa photos during Christmas and the covid immunization sensory sensitive initiative have also been helpful. However, my fears for Sophia living in a remote place in the north is that she won't have access to the same resources as in other places in Canada. At the same time, I know she's in touch with her culture and that being in a remote community allows her to stay in touch with her roots and who she is as an indigenous girl. I worry the world will try to bring her down, but I know she's capable of conquering those things. Being around people who are non-judgmental and understanding of the roller-coaster it is to live with someone on the spectrum has really helped us.

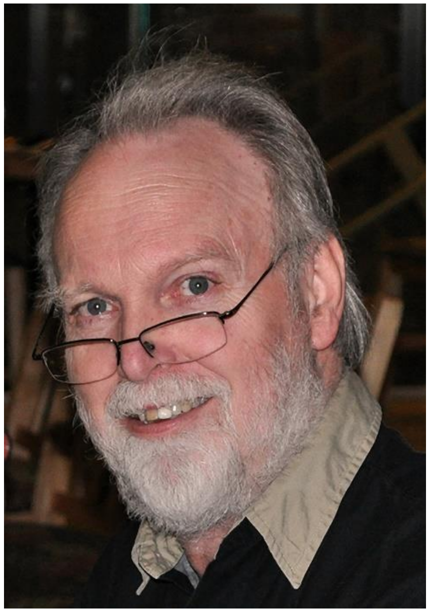
An ideal life in Yellowknife would look like awareness, acceptance, and our community being able to interact with our children. There's so much pressure on our children to adapt to societal norms, so I would like to see our community adapt to our children and their needs. I'd also like to see an increase in opportunities for kids with diverse needs to access activities just like any other child.

I think inclusion means self-analyzing your own feelings about others. When you're able to accept someone else for who they are, that's when inclusion happens. Inclusion means understanding that people need some adaptations in order to be the best version of themselves. My advice for others is to never lose sight of your child's potential. Never lose sight that you're fighting for a human, not a label and that there are no limits on our kids aside from the ones we place on them.

Bert: *I don't think that having one grandchild that has a disability has taught me anything special, only that you just have to be honest with your love all the way around. My thinking is that the grandchildren will all have differences in some way or another, and you just try to love them all equally. Children with disabilities just have issues that have to be handled in a different way. That's all. What you hope for any of your grandchildren is that they reach their full potential. It doesn't matter what that is. You've got to maximize their full potential.*

The fear that I think most parents have is that their child will not grow to be independent, or that they will not independently be able to look after their child any more. The same thing goes with Emily in terms of her being able to remain independent and still look after Sophia. If that becomes an issue, I am confident Emily will have the strength to have a plan in place to take care of Sophia. I think there is a fear of the unknown for Sophia in the long term, but you have to live with what's happening today as opposed to just focusing on tomorrow.

Cornelius Van Dyke YELLOWKNIFE



"Inclusion would be living in a world where it doesn't make a difference whether I'm in a wheelchair, or whether I'm walking, I can access the same services as everyone else, and there's no penalty to me."

My name is Cornelius Van Dyke, I live Yellowknife, and I have been living here for close to twenty-eight years. I am active, I am a senior citizen, I am an architectural technologist, I'm a father, I'm a husband, and I spend my day in a wheelchair. I like to get out and explore Yellowknife. Every year, I try to get around most of Yellowknife, just to see what's there. I like to take pictures of Yellowknife to show where I've been, what I'm doing, and what has changed. I like to sit in some of the quiet places that I find around Yellowknife.

I am a person with a disability; I was diagnosed with Multiple Sclerosis in 1998, so I've been living with a disability for twenty-five years or more now. Although my disability is very visible, in that I'm in a wheelchair, I am not disabled. I am able to do as much as I can, so I don't want to be seen as a disabled person; I want to be seen as a person who is in a wheelchair. Since I was diagnosed, I am better for it. I see things differently than other people do, I think I'm a little more accommodating and understanding because of it. My advice for others is to be strong, look on the bright side of things, and that disability doesn't mean you have to stop being who you are, or what you are. If I was younger, I would still have dreams of travel, flying, and golfing. There's all sorts of opportunities available to you if you're willing to chase them.

I've only had two employments while I've been here in Yellowknife. I worked for an architectural firm for just under twenty-five years, and they were very accommodating and they were very good. When I first was diagnosed and was in a wheelchair, they set my office up on a ground floor and I had access with a ramp. I could get into the washroom, as it was wheelchair accessible, and they accommodated my needs without any questions. My second appointment is I'm self-employed and working from home keeps me pretty busy, happy, and active. I'm past retirement age, so what we are looking at in the future is reducing my work. I still work, you know, probably thirty-five-forty hours a week, and someday I'd like to reduce that, especially in the summertime, so that I can get out.

My diagnosis has 100% affected my life because there's a lot of things that I can't do on my own, there's a lot of places that I can't go on my own, and I need assistance in a lot of day-to-day activities. So in every moment of every day I am aware that I have a disability to deal with. Generally speaking, people accept me; if people see that I am trying to get into a building, they'll help me. They generally see my wheelchair as something to accommodate so they've been good at that. I find getting out in the winter time is impossible. I love golfing, but can't do that anymore, but as far as in the community, I can go where I want to go and I can do what I want to do. When people learn I have a disability, people, generally *speaking, respond with caution, but then acceptance because I would say 95% of my work is on the computer. I can work anywhere, because I have a computer, and as long as my computer is set up for my accessibility, I'm doing fine.*

Living in Yellowknife as a person with a disability is sometimes frustrating and sometimes okay. Accessibility in Yellowknife could be improved. There's a lot of stores in the main drag that are impossible for me to get into, unless someone is with me. It's also frustrating in that the winters are so long and it's difficult to go outside in the winter with a wheelchair. It's hard to go on sidewalks because of the snow, and in most cases Yellowknife is accessible, but there are a few places where it's not. It's nice in the summer because I can get around. Today is the first time I've been outside by myself, but the roads are awkward in a wheelchair, because of all the gravel and stones on the sidewalk. It's very difficult or uncomfortable to bump around, but generally speaking it's okay. In my line of work, sometimes going to sites to view construction of buildings is impossible for me to do, but that's the only thing, because I'm largely working on a computer and that gives me access to everything I do.

For me, being included means that I wouldn't have to phone ahead to find out if a building is accessible. I wouldn't have to look at a notice board that's too high off the floor to read when trying to find directions in a building. It would be living in a world where it doesn't make a difference whether I'm in a wheelchair, or whether I'm walking. I can access the same services as everyone else, and there's no penalty to me for it.

I haven't come across any beliefs I wish were different or that I would want changed about my disability. Once people meet me and understand that I'm just the same as everybody else, they're pretty much fine with who I am. I've never had a fear about disclosing my disability. There are fears that I have for my future, because I don't know what the future holds. I don't know what my disability will do to me in the future, and like I said, I need assistance for doing many of the day-to-day activities, and my wife does that most of the time. But what happens when my wife is not available? That's the biggest fear. My other fear is that we're living in our own home at the moment, but what happens when we can't take care of ourselves there? Those are my two biggest fears.

The biggest message that I can think of for others is don't hold back. I've seen programs and I have read about people that have rafted up and down the Grand Canyon in wheelchairs. I've read books about people that are flown across Canada by themselves in their own airplane. I've seen stories of people rock climbing in a wheelchair. Just because you're in a wheelchair, just because you have a disability, it doesn't limit what you want to do. You have your dreams and pursue them… and always smile!

Lynn Hanthorn FORT MCPHERSON

"For me, being included means recognizing where a person is at and making adaptations and providing the support that's needed for that individual."

My name is Lynn Hanthorn and I have lived in Fort McPherson, NT for the past thirty-two years. I'm a mother of seven biological children, three adopted, and dozens of foster children. I have devoted many years to raising and educating my children. I presently live with two twin girls who have been diagnosed with FASD. As a family, we like to be outside a lot; I think it's important and healthy for kids to be outside, so I make an effort to take my children outside daily. We enjoy all sorts of activities including berry picking, camping, long walks, swimming and playing in the mud along the Peel River. In winter, we enjoy skating, sliding, and cross-country skiing. We also participate in community events and local activities when they happen. When my children experience cultural activities, they feel proud of their heritage. In our home, we do creative activities like crafts and art regularly- right now, my children are learning beading. All of these activities contribute to their self-confidence and joy of accomplishment. It brings me much joy to see my children grow and develop and overcome challenges as they learn new skills.

For me, being included means recognizing and accepting where a person is at developmentally and then making adaptations or providing the support that's needed for that individual to participate, grow, and learn. I care deeply about helping children with disabilities so that they can get the much-needed help that they require to develop to their full potential. I have experience with children with disabilities as a parent to my own children and in the work that I have done both in the school system and in foster care. All children with disabilities have some unique needs and require individual adaptations.

One thing I have learned is that you cannot always see a disability, especially when it's a mental disability like FASD. Outwardly, my children do not look like they have a disability, but in fact they have a significant disability. Understanding my children's inward disabilities and adapting to meet those needs is just as important as putting in wheelchair ramps for children with physical disabilities. My children require a lot of supervision, close assistance, and repetition in order for them to learn, be safe, and follow routines.

The FASD diagnosis impacts my children's lives significantly. One way is that it takes them longer to learn things and it takes more effort and perseverance to do the same things other children can. Because of their disability, they can become frustrated and angry more easily. They regularly have "off days". On their off days it looks like they are being uncooperative and simply "bad," when in fact they are working just as hard as they do on their "on" days. Another example of how this *disability impacts my children is that they struggle to pick up on social cues, which makes it difficult for them to make friends and keep friendships. They are highly sensitive to any remarks made and may not understand jokes or teasing, which results in an angry or aggressive response. Similarly, because of huge developmental delays, they are not as able to interact with peers their own age, so they generally interact with kids who are much younger than them. I understand this and accept it, but others often don't understand these challenges.*

At first, I struggled with parenting my children with FASD because I didn't really understand the challenges of FASD and how it impacted them. Learning as much as I could about the disability was and still is important for me. Once I learned how the brain was impacted through FASD, I was able to better help my girls. I was able to understand their behaviour and respond in more helpful and supportive ways. I also found that I was better able to parent when I separated the children and when I could have a break from parenting. It is stressful living with this level of constant need day in and day out. Having a break is vital for the health of parents of children with disabilities.

As a parent of children with disabilities, helping my children grow and develop can be time consuming. I don't think people always understand the level of involvement it takes when you are caring for children with disabilities, but this extra time and effort is essential for these children to learn and succeed. Other times, this extra effort is put in just for their own safety and the safety of others around them. Aggression is something we live with on a daily basis. For many years, it was tough because we didn't have any breaks and we had a busy home. We don't have extended family here in Fort McPherson and finding someone in the community who could consistently show up to help was challenging and/or costly.

The respite support I now receive through the NWT Disabilities Council has been life-changing for myself and my girls. The worker I have has been in my children's lives for many years now and her consistency has made a huge difference. I get a much-needed break, and yet the girls' learning is not interrupted. Our respite worker helps to homeschool our girls' and she has provided remarkable support. I feel like they've learned some concepts that I didn't even know that they would ever be able to learn! I'm very thankful for that and I am convinced that they're able to learn more effectively this way than in a school setting. When my children were in the school system, they were not recognized as having a significant disability, so they were falling further and further behind because they were not getting the support or individual help that they needed.

Homeschooling effectively is only possible because of the support I receive through respite. I struggle to teach the two of them by myself as their behaviours and needs are so challenging. My desire is to continue homeschooling my girls until they're done high school and what we have with respite support and a consistent worker is an ideal situation right now. I know that many others don't have any help, so I'm very thankful for what my girls and I have. I'm sure it's very hard to find this level of support in many of the other small communities.

There are a few other struggles we are presently facing. First, I find that there is little perception from others in the community that my children have disabilities; this stems from their healthy physical appearance of not having a disability. This can make participation in community activities difficult. I must be present when my children attend community activities because they *need that higher level of supervision. It is awkward to have a parent present at a youth event! The reality is however, when my children are at community events, they struggle to pick up on social cues and often interpret situations wrong. With little impulse control they easily can become angry and even physically hurt others.*

Secondly, I find that people tend to avoid my children because it takes more effort to engage with them. I really do appreciate it when people take interest in them, rather than being annoyed or critical. There are a few people from our community who always go out of their way to acknowledge the girls and do things like bring them muktuk when they have some. Another lady made them mukluks for Christmas. These thoughtful acts of kindness mean a lot to me.

Lastly, another challenge we are facing now is that my children have difficulty sharing their home with younger children. I now have young grandchildren and it does not always go well when I bring them over for a visit. This can be difficult and requires a lot of supervision and preparation. Similarly, I am still interested in having foster children, yet my children struggle to accept younger children in their space. When younger children are simply acting their age, they have a hard time tolerating their behaviours, even though they display some of those same behaviours. This can make it difficult for our home to be as open as I want it to be.

Helping our children understand their disability has been challenging. We haven't talked to the girls much about their FASD diagnoses. We haven't said to them, "you have a disability," but I think, as they get older, they will become more aware of their differences, and we will talk about it more. I do worry about what the future looks like for my children. I get concerned about what they will be able to do independently. Will they be able to work? Will they be able to mature enough to be able to make wise, healthy, and discerning decisions? They seem to have a bit of an addictive personality, so I get worried about what they would do if all their supervision and restraints were removed. At this point, I don't know what's available for adults with disabilities and that's something I need to explore. I hope there's supportive opportunities available because I have a feeling that they are going to need support as adults. It would be great if my girls were able to have access to someone who knows how to teach a person with disabilities how to live on their own someday. As a parent, I would also like more training on how to best support them as they age with this disability. Because it takes them so much longer to learn skills, I can see how important preparing my children for their future is. It is my goal and devotion to help my girls be as healthy and productive in the future as they possibly can so they can have happy and healthy lives.

Sunil Sriram YELLOWKNIFE

"I'm very open with everything and don't see myself as having anything wrong with me. My advice for others is to do what makes you happy. Set a goal and do everything you can to achieve it."

My name is Sunil and I have lived in Yellowknife all my life. I like to think I'm a very chill and optimistic person. I like playing sports like soccer. After I graduated high school, I took business courses at Aurora College. My goal is to get a job with the government here. I want to do this project because it's a good way to connect with my community, get my story out there, and maybe even help me gain employment.

I was diagnosed with cerebral palsy when I was born. The main part of my disability involves difficulty with my fine-motor skills for things like writing. I think the main difference for me is doing things like writing, because this takes me longer to do than others. Otherwise, I really don't see myself as having a disability, because I, luckily, don't find it that bad. In general, I feel like I can do pretty much anything the same as anyone else.

Growing up, school as both a child and a teenager was hard because I was pretty hyper and got into trouble sometimes because of it. However, I wouldn't say living with my disability has affected me negatively, because I'm still able to do the same things as other people. I find I don't tend to worry about my disability or pay attention to anything negative others may think about my disability. I hang out with good people, and I just go out there and do my own thing. Living in Yellowknife, I don't find it too challenging, because I like to stay active and walk and not be too dependent on the bus system here. I like living in Yellowknife because it's small and friendly, so everyone knows each other and it's easy to meet others.

I think the biggest challenge for me right now is in employment. After I finished high school, I got more serious about my education and learning about business. I worked in finance with the GNWT before as a summer student, but it's such a narrow job market I couldn't get a full-time position after that. Even though I have taken these college courses, and lived here all my life, it is still difficult to get a full-time job. I think we need to give people with disabilities more job opportunities, especially in more reputable jobs. So many people with disabilities are so smart and able to do more than what is available to them now. I've never had any fears about having a disability or telling people I have a disability. I am lucky because everyone has been accepting about my disability and I've never had anyone give me a hard time or bully me about my disability, but I know this isn't the same experience a lot of other people with disabilities have. I'm very open with everything and don't see myself as having anything wrong with me. My advice for others is to do what makes you happy. Set a goal and do everything you can to achieve it.

Paula and Gus MacKenzie YELLOWKNIFE

"For me, inclusion looks like no barriers to anything, having equal opportunities for everything, and not having to push for the things that others take for granted."

My name is Paula MacKenzie and I've lived in Yellowknife for seven years with my husband, Jason MacKenzie, and our two children, Finnley and Gus. Finnley is seven years old, and Gus is four and a half years old. Gus is an easy-going kid and always so happy and easy to be around. Gus loves playing with water. Gus also is a big cheerleader for his brother, Finnley, as he comes to watch all his activities. When Gus was just under two years old, he was diagnosed with Bohring-Opitz Syndrome. Bohring-Opitz Syndrome is an extremely rare condition; in fact, I think Gus is the third person with Bohring-Opitz Syndrome in all of Canada. Gus and I wanted to participate in this project to help other families know about options in Yellowknife and to be supportive to families with a child with a disability.

Before Gus was born, I did have some experience with disability. I first connected to somebody with a disability when I was in university. In university, I worked with L'Arche in Whycocomagh, Cape Breton for the summer. L'Arche is an organization that runs a housing program where people without disabilities work in live-in positions with people with disabilities. From this work, I did have some understanding of disability. However, when we first found out about Gus' diagnosis, it was new to me because it was so rare. It was really an educating moment for me and my husband.

When I teach people about Bohring-Opitz Syndrome, I explain that being non-verbal is a major part of it. Gus is non-verbal, but I explain that as Gus' family it is easy for us to know what he wants because he has his own way of communicating with us without words. Gus is on the milder end of the spectrum for diagnosis. Aside from being non-verbal and wearing a leg braces, I don't think anyone would know that Gus has a disability. Gus looks the same as anyone else when he's walking, so I don't get a lot of questions from people about his disability. I think we're at a point now in our life where we have it all set and organized and we have all the support that we need in place, which has reduced our stress.

It took us time to get to a point of having the support we needed organized. It was a big learning curve with what we needed to do and what we needed to know. Planning all the medical appointments was a big stressor in the beginning, but now it is more of a routine and a lot more manageable. Since coming to Yellowknife, our family has benefited a lot from receiving intervention services. My husband, Jason, is in the military. We have decided to stay in Yellowknife, even though we had the option to be posted out, because of the quality of care that Gus has received through the NWT Disabilities Council's Early Childhood Intervention Program. Through the Early Childhood Intervention Program, Gus receives support *one-on-one with an intervention worker who works towards individualized developmental goals. Gus has greatly benefited from this program. He's made huge strides, which in turn has made our life easier, especially with him walking on his own. That is a big achievement, and, even if he doesn't improve or learn anything else, at least we have this, and it's made a huge impact in our lives. The program has been so beneficial that we have decided that he is going to stay in it until he ages out. After that, we'll enroll him in school.*

Our feelings about Gus' disability have changed since the beginning. At first there was a lot to learn, and it was a change for us, but after a couple of months, Jason and I just began to take life day-by-day, rather than fixate or worry about all the complications that might arise. We had lots of concerns at first but realized that there's really no point in worrying about these things because they may never come to fruition. Gus' disability, however, does continue to impact how my husband and I envision our future. The biggest thing for my husband and I is what will happen to our family when we get older. Jason and I are almost in our fifties now, so we want to make sure Gus is taken care of. We're not concerned about his happiness because he's a very happy kid. We actually would love for him to be in L'Arche, where he can be taken care of, and we can visit him.

We also have some more short-term changes coming in our lives that we have some concerns and apprehension about. One thing that concerns us is that the one-on-one intervention support that Gus gets now is very different than what it will be at school. Part of our hesitation is that if we enroll Gus in public school, his one-on-one support will be more of a babysitting service. We want to make sure that Gus can interact and continue learning new skills without feeling like we're getting a free babysitter. Our goal for school is to continue the social interaction, which Gus really enjoys in his intervention program. Another roadblock we are facing with school enrollment is after-school care. Every after-school program we have found has told us that support for Gus depends entirely on whether they have enough staff for someone to work one-on-one with him. If the programs decide that Gus is too high needs for the number of staff they have, we will have to find another option, which will be really difficult for us even though we are willing to pay for it.

We want to make sure that Gus has an equal opportunity to everyone else and that he'll have the support he needs. I wish that there were more options for children with physical limitations in Yellowknife. When we first came here, there wasn't an accessible playground, so it was hard to find a playground that worked well for our family. I think that there is still more that could be done for making more options for kids here.

If I had to give advice to other families, I would say that even though it is very scary getting any kind of diagnosis, focus on the positive and not try to stress over "what if's" that may never happen. You could waste hours, days, and even years stressing about things and miss out on the positive things. Gus' disability has been a very eye-opening experience and it's made my oldest son very empathetic and understanding. There have been many positives.

Ashlie Forget YELLOWKNIFE

"Being included is being allowed to participate with other children and being given the same opportunities as anyone else to succeed."

My name is Ashlie Forget. I have lived in Yellowknife since July 2021, and am originally from Nova Scotia. I have three children: Lucas, Aurora, and Jack. Jack is my youngest and he has suspected autism, ADHD, and speech delays. Despite these challenges, Jack is such an intelligent little boy. He is so passionate about learning and discovering things. He loves dissecting things and understanding how and why they work. Even though he can't communicate verbally, Jack has adapted to being able to tell people his needs and wants with nonverbal cues, so he's very good at telling you what he's thinking. I wanted to participate in this project because I want to advocate for other children like mine. I want to use my voice as a platform to spread awareness and help foster inclusive relationships with other community members.

I met my husband in high school and he had ADHD. My husband was the first experience I ever had with someone with a disability. Thirteen years later, two out of our three children have ADHD or suspected autism. My husband doesn't overly like to use the term disability; instead, he likes to say that he has a different way of seeing the world that not everybody else does. He blessed us with two children that are so like him and it's amazing watching them together. My husband and my children see the world differently and when they explain it to me, from their perspective, it makes so much sense and it just blows my mind.

I come from a province that has a lot of gaps in their processes for assessing children with disabilities and a lot of gaps in education for parents and teachers. When I came to Yellowknife, the first thing I realized was that the school system here has smaller classroom sizes, which is perfect for my oldest son, Lucas, who has ADHD, ODD, and anxiety. Back in Nova Scotia, I never dealt with an organization that was specifically for advocating for people with disabilities. It made a huge difference when I came to Yellowknife and reached out to the NWT Disabilities Council. When I dealt with the Council, I was then able to tell his strengths and weaknesses and start working towards supports. Around the same time, I was also able to speak to a doctor and we were given support right away and referrals were sent immediately. I will never be able to express my gratitude for how it worked here versus how we were just waiting for everything back home in Nova Scotia with my oldest.

I think the biggest thing I want other people to know is that, even in 2023, it's still not inclusive for children with disabilities. I don't think a lot of people know this. There are still so many hurdles for any sort of disability or delay. I think that a lot of parents don't understand the struggles of the extra hurdles and steps that we must take to meet the needs for our children with disabilities. For example, with Jack, we do not have access to childcare in the way that is required for my job. While getting *my nursing diploma, I worked very hard even though I was pregnant with Jack and raising my other two children. Once I moved to the workforce after graduating, I struggled to find childcare for Jack. I struggle to fulfill my commitments at work and further my career. In today's day and age, nurses are really needed, and I can't help my community in the ways that I want because I don't have reliable childcare.*

Keeping Jack in childcare is super hard. I feel that as soon as he goes somewhere new, there is apprehensiveness once the childcare centre finds out that he will be accompanied by a one-to-one worker from the NWT Disabilities Council. Once they find out he has an intervention worker and he has a disability, I find that they have a lot of preconceived expectations of how Jack is going to behave. It's frustrating because it seems that when he is put into this box, a lot of his behaviors are made into something more than they are. For example, Jack has a hard time with transitioning, like other children his age; however, when Jack has an issue with transitioning, he's labelled as 'having a meltdown', whereas, if another child does the same thing, they're just having an off moment. I think this leads to the children treating my son differently since they are being taught that people with disabilities are hard to deal with. It's because of situations like these I fear sharing his diagnosis.

Inclusive childcare is important because it gives children the chance to socialize with others and foster new relationships. An ideal life would be very similar to what we have now in Yellowknife, but with more childcare providers that are receptive to working to educate their staff on disabilities. To me, it feels like there's an education deficit with childcare providers and that they fear what they don't know. In some cases, children with disabilities are being excluded from programs altogether. In a world where we're seeing a lot more children that have disabilities, there needs to be more of a push for childcare workers to further their education on disability and supports.

Things changed a lot for us after we moved to Yellowknife. We became our own little team when we moved here since we didn't have the family and friend support anymore. I notice that we've gotten thicker skin since moving here because my husband and I have advocated for our kids a lot more than we used to. We're realizing that when we ask for help, we're actually getting it now. I am learning to see the way that my children need to be supported and I am more comfortable voicing those needs and making sure they are met. I've also learned that part of being an effective advocate for my kids is being receptive to new resources and education so that I can get to be the best version of myself that my children need me to be.

My older son, Lucas, generally gets amazing support while at school. One thing that is still a bit difficult with Lucas is that I don't necessarily get reports of when he has any challenges at school until he's told me. This can be a bit frustrated because I want to know what's going on and if I don't know about my child's behavior, I can't correct it. I'm always open to anything they need to tell me, and they are starting to get better at reporting any sort of challenges, but it's still like a day or two later that I'm finding out about these issues. Jack hasn't gotten to school yet, but I have him registered for September and I am confident that they're going to welcome him with open arms. My biggest fear with Jack going to school is him not being able to tell me if he's treated differently because of his nonverbal language. Children like Jack can't tell us when they're not being treated properly. I fear that adults may not treat Jack in the same way as other children. My biggest fear would be something like that causing Jack to have mental health consequences and stop acting like his normal passionate self.

My advice to parents is to keep pushing and advocating. Don't let anyone quiet you because you are your children's voices. You need to bring awareness and to advocate for them because they cannot do this for themselves. We need to break the stigma around disability, and we need to show that our kids are here and are entitled to the same access as other children. Being included is being allowed to participate with other children and being given the same opportunities as anyone else to succeed.

Sandra Noel YELLOWKNIFE

"I feel most included when people see me first, not my disability... Inclusion gives me a sense of belonging. It gives me hope. Inclusion lets me know that I am loved and valued by everyone around me."

My name is Sandra Noel. I was born in Inuvik and currently live in Yellowknife. I have lived in Yellowknife on and off my entire life, some of which was in the foster care system. I moved to Yellowknife permanently in 2011. I am a wife, a self-advocate, and an adult living with Fetal Alcohol Spectrum Disorder (FASD). The reason I wanted to participate in this project was to tell my story so that I can give others courage and to spread the message that there is hope. At this point of my life, I am still learning about myself, how my mind works, and what works best for me. I want everyone to know that people like me are not alone and we are all worthy and capable individuals. I want people to know that there is no shame in living with FASD.

I was diagnosed with FASD in 2020. Finding out what disability I had really helped me to understand myself much better. My diagnosis has helped me to understand why I struggled so much with certain areas within my life. Growing up as a child in foster care was very challenging and I also often found school to be difficult for me. I think the workload was overwhelming for me and the teachers had a difficult time supporting me because they didn't know I had a disability. I'm not sure if they knew how to help me very well. It actually took me an extra year to graduate from high school, and, although I attended Aurora College, I wasn't able to complete an entire program there, besides their Social Work Access course.

Before learning of my disability, I was going down a life path that was not healthy for me. I started abusing alcohol, doing drugs, and making poor life choices. I also didn't know what accommodations I needed within a workplace environment to experience ongoing success. I had several instances where my job wanted to promote me to a manager position. Unfortunately, I wasn't given proper training, so things felt overwhelming when new responsibilities would be added to my workload. One workplace in particular didn't provide me with enough training, so I was left feeling unsupported in my desire to become a manager. Since I didn't have proper training or a positive and supportive work environment, I ended up leaving that job.

After experiencing these challenges, I came to a realization that I wanted a better life for my husband and I. Deep down, I guess I just knew that there was something better for me out there. Getting an official diagnosis gave me access to resources and supports that have made my life better. I now like to spend my time raising awareness about FASD and what life is like living with an invisible disability. I'm part of a committee with CANFASD, which is a research network for Canadians with FASD, I'm involved with a national youth program through the Child Welfare League of Canada, and I'm also currently working with *the Foster Family Coalition as part of the Rise Up team, which helps to raise awareness and spread the word about anti-racism and anti-discrimination.*

When I look back, I think things could have gone differently if I had more support and resources that I needed. I often hold myself back because I become fearful that I'll become overwhelmed with the workload and things will be too hard for me to experience success. So if I were to go back to school, having good financial support and having a classroom or educational assistance would be extremely helpful. I would feel less anxiety and fearfulness if I knew I could have someone transcribe for me or have access to a tutor. Knowing that I could have access to those resources would decrease a lot of stress from the unknown and the idea of pursuing further education for future employment wouldn't seem so unachievable.

I want to let others know that they can always make the decision to choose a better life for themselves. There is hope and you don't need to be a statistic just because you grew up in foster care or because you're living with FASD. Having a disability is not a bad thing. Getting a diagnosis gives you answers and will better help to support you throughout life. Reach out to local organizations because they are there to help you. Each resource has helped me make sense of who I am. Being a First Nation person, learning about my FASD has helped me throughout my healing and recovery process from the intergenerational impact and trauma connected to residential schools.

For me, inclusion is being both invited and included in projects like this one. It's being in an environment where I feel welcomed and supported, not shunned, excluded, or stigmatized by others. I feel most included when people see me first, not my disability, and when I'm around others who don't make me feel less than them. Being included is important because it keeps me and others like myself from feeling alone or depressed. Inclusion gives me a sense of belonging. It gives me hope. Inclusion lets me know that I am loved and valued by everyone around me.

Tiffany Davidson YELLOWKNIFE

“Inclusion is creating a space to feel welcomed with the understanding that we all should be afforded the same opportunities and work to not level the playing field but to, instead, create new fields so that everyone can feel safe and welcomed in their environment.”

My name is Tiffany Davidson. I moved to Yellowknife in 2017 and lived in Halifax before that. My son, Nash, is a super fun, affectionate, and bubbly little boy. We’ve recently received a diagnosis for Nash of Autism Spectrum Disorder and Global Developmental Delay. The thing I would like most for people to know about Nash is that, even though he is nonspeaking for the most part, he understands everything that's being said. He's a very intelligent little boy who moves to the beat of his own drum, loves to dance, gives the warmest hugs and is so much more that his diagnosis.

I wanted to participate because I know that many people from the lens of a neurotypical person don’t necessarily know the challenges people with disabilities face every day. My husband, Alex, and I weren’t fully aware until we were thrust into it with Nash, then, all of a sudden, it became very clear very quickly. I feel a sense of duty to both my son and also to the community to shed light on these challenges. I'm trying to guide him as best I can and trying to help his support staff understand that we're not trying to cure him. We're not trying to force him to do certain things or conform to what society feels is acceptable. We’re enhancing his quality of life and experiences through the way that he wants to live them. I think it's important for people to realize that it's not about trying to make autistic children conform to neurotypical standards, it's more about how we can celebrate their differences in a way that is comfortable for them.

It's funny because after having a bunch of conversations, we realized that it’s quite possible that I am also autistic. I strongly believe that if there was more awareness ahead of time I probably would have identified as somebody who had challenges my whole life, but I just chalked them up to being different. It really felt like it hit home even as I was learning about Nash and his needs. Participating allows me to share both my son’s and my own personal experiences in the hope that someone will have access to information sooner than I did.

Disability impacts us in an overall positive way; it makes us resilient and tighter as a family unit because we lean on and support each other. There have also been some challenges. For one thing, I had to quit my job and now do part-time work from home to accommodate the level of support Nash requires since after-school programs weren't an option for him. It also challenges us in the sense that we can't necessarily do things that we once did as easily as we did before. Unfortunately, society is not really made for people with disabilities like Nash. When we’re out as a family, the simplest things can be barriers for us to participate. For example, open doors, standing in line or the judgement that can come from stimming.

COVID was really hard for us too because he was unable to wear a mask, so for the last two years we've basically been inside and not able to travel. I think the disabled community was hit really hard. We couldn't really go anywhere that required a mask, so there were a lot of barriers that were in place for someone like Nash. When you're constantly in these positions, you learn quickly that you pick your battles. Sometimes waiting on others to find a solution brings about more anxiety and stress and sometimes leaves you in a worse position. You can find yourself getting a little bit defeated.

Initially, I had fears disclosing Nash's disabilities because it was so new and unknown, and I hadn't come to terms with it yet. Now, I want people to know that he's coming from a place of honesty and not one of him being labeled a 'bad kid'. Caring for an autistic child can demand a lot of energy and time and I found that I also became very guarded and protective of Nash. It's a journey and it doesn't become easier. It can be in fact grief and heartbreak by a thousand papercuts, but it does become more manageable. Now I find it's helpful to say that he's autistic, to say that he is wired a little differently, and he is going to experience things in a different way. This way, if he does scream, or flap his arms, or twirl around, people understand that it's ok and it's just part of who he is.

We are finding people in Yellowknife to be very supportive. Right now, we've received support from The NWT Disabilities Council, Inclusion NWT and Special Olympics NWT but I would say that there's definitely a lot of work that could be done around inclusivity and making things more affordable for families caring for someone with a disability. A community space where parents of kids who have disabilities can get together as a support group and have a safe space where all of our kids can be present with each other would be amazing. I also think that more funding would be helpful to parents like me who have had to leave full-time work to support our kids. Support for one-on-one after-school care would be a major help for us, as well as an inclusive camp that is put in the budget, staffed, and available to anyone who needs it. What is not widely discussed or understood is that kids like Nash have very limited options for summer camps, March break, Christmas break, PD days, etc. So, it leaves parents in a very difficult situation emotionally and financially. Also, just having more options of places to go would help, because we are in the north and it's cold a lot, which limits outdoor activities, but there's not a lot of organized indoor activities for families that accommodate invisible disabilities, like Autism.

Talking about disabilities can be an uncomfortable topic because people don't know what to ask. I think that with exposure to people with disabilities, everyone will become more comfortable with inclusion. School has been really good; we have a Child Development Team Lead who has been a wonderful pillar that we can go to with all of our questions. Before we started school, we had a meeting that she coordinated with Nash's school, speech language pathologist, occupational therapist, and the School Board's Inclusivity Director so we had a great blueprint as to what going into school would look like, which was a huge relief and help for us. Communication has been paramount. We have an app that we talk back and forth on, so we know how school's going. We've seen a lot of improvement in Nash's play. He loves to paint, participate in 'Fire Fridays' and explore all of the sensory items in and out of the classroom. They've been very inclusive and creative in ways to include him.

When it comes to the future, our main goal is getting him to a spot where he can function in his everyday life without us, because we don't have extended family here. This is one of those papercuts I discussed earlier. Lifelong care is a topic we didn't see in our future when we first held Nash as a newborn. We envisioned all the milestones that would come with watching your child grow into adulthood. We didn't foresee the endless therapy, appointments, mountain of paperwork or the journey *of grief that we would endure, especially, when terms like 'Life-long Care' were discussed. We've gotten to the point where we need to really be blatantly honest and transparent about Nash's needs with our family members and community. As we get older, we have to put money aside to make sure that he's cared for. Everything is unknown at this point and there is a delicate balance of being present but also preparing yourself and your child for when we aren't here to guide him.*

My advice for others is to be honest with yourself and to ask for help when you need it. Celebrate the positives as much as you possibly can because there's a lot of negatives that are directly or indirectly thrown your way. I would also say don't forget about taking care of yourself first. It's like the oxygen masks on the airplane: if you don't put your mask on first, you can't help your child. Make sure that you take care of yourself for the whole journey because it's not easy and it's long. Having a child with complex needs is challenging but its also the greatest gift, we wouldn't change Nash if given the chance. Our only aim is to remove barriers, improve his quality of life and set him up for success in the years ahead.

Inclusion means being treated like people want you there, that, rather than being judged for your differences, your differences are celebrated. Inclusion means that there is an understanding that everybody is different and that's okay. Inclusion is supporting everybody when it's needed and when it's asked for. Most importantly, Inclusion is creating a space to feel welcomed with the understanding that we all should be afforded the same opportunities and work to not level the playing field but to, instead, create new fields so that everyone can feel safe and welcomed in their environment.

Denise McKee YELLOWKNIFE

"Inclusion means being a human being whose human rights are being respected."

My name is Denise McKee; I am originally from Hamilton, Ontario and moved to the Northwest Territories in 2009. We first lived in Aklavik, and then we relocated to Yellowknife, where we've lived ever since. I am 60 years old, and I identify with a disability myself. I have been married for almost 30 years to my husband and I have four adult children, who are two sets of twins. My two daughters are 26 and my boys are 25. Three of my kids identify as having disabilities, but for this narrative, I want to focus on the oldest of my boy twins, Conlan, simply because his needs are the most complex and he's experienced many more challenges. I want to participate in this project to lend observations and information that the community at large doesn't know about.

My son Conlan is a wonderful, smart, and empathetic young man, who is autistic, has mental health concurrent challenges and diagnoses, and has complex communication developmental delays. Conlan loves seeing people happy; he's an incredibly hard worker and problem-solver. He loves traveling, woodworking, exercise, and music. I want people to know disability doesn't define him; he's disabled because his various impairments present in a way that if he doesn't have accommodations made, it can be disabling for him. However, if we're able to have those supports in place, he thrives and excels. Unfortunately, I do however think the limited resources that are available in the north prevents him from reaching his full potential.

When Conlan was in school, we found we were always ahead of the curve of the individuals who weren't trained specifically for people with disabilities, because it was our life. Conlan received his diagnosis when he was 3 and it was well before most people had a real grasp of what autism is. It was a normal experience that we would know much more about autism than the staff that were assigned to work with Conlan. School in Aklavik was initially challenging for Conlan because his needs were more complex than what they'd seen before; however, there was an open-mindedness to just sitting down and working together, which did help him. After we came to Yellowknife, high school was overwhelming. After the first year of his enrollment, our family found out that the school didn't have any of his documentation, not even have the intervention plans I myself had written to help him back in Aklavik. Indeed, we found out that they knew very little about Conlan and this was causing behavioral issues all the time because he was bored and being kept in a class that was basically a punitive room. I found that when I advocated for Conlan, the school was often very defensive. I felt like the school did not want to deal with my family at all. Although dealing with the school was challenging, after some time, it did finally lead to him getting a new support team, which finally led to him thriving.

As a family, we do everything we can to enable him to succeed, but there is systemic prejudice and discrimination, and lack of understanding that prevents him from being a full citizen. Accessing supports is very difficult and families have to often resort to the most abject portrayals of their child to access them, which put emphasis on weaknesses rather than strengths. Supports can make a world of difference but are often uncertain or temporary as they depend on certain eligibility requirements like age or income and may end at the end of a fiscal year if funding is not renewed. When these supports disappear, it's challenging and disappointing and creates new challenges. Conlan had a lot of support with early intervention when he was young, but it seems that, as a person starts to grow and age, they become less significant to society, and as a teenager we feel less responsible for their wellness. When they reach adulthood, it's like they've disappear until they become important again. So, during that interim between 18-65, those years are spent just trying to cope and spent doing menial jobs or day programs that don't necessarily meet the interests of the individual. Nothing is more apparent than in this territory than the fact that we too often send adults with mental disabilities to southern facilities, so they're not seen and they're not our problem anymore.

Most families don't experience this or realize the fears and the fight we must do for our children. From my professional experience in the north, the navigation here in the territories is just overwhelming; you don't necessarily get services and it's heartbreaking to hear of families that don't get the supports or advocacy they need. Families and advocates must change their approach to whatever government is in power, what doctor or school we're with, because the people on the other side of the table feel like they're being challenged. And if you speak out, as a parent or a professional, there are repercussions. I look at activists who came before me in any challenged community, and I see their bravery in the fact that they placed their own wellbeing at risk. My husband and I were relieved when the kids turned 18 and could be legal guardians for Conlan because we understood we didn't need to be worried anymore about him being abused or neglected or in some kind of institutionalized care where someone is in full control of him, and he just withers away.

I find that when people realize that Conlan has a disability, they tend to defer to me to answer questions about him, rather than asking him directly, so it's almost like they don't see him being able to answer. When people do this now, I'll go to ask him the question, which sometimes will cause a shift and get them to interact with Conlan too, which is nice. Some people have a more open attitude and there's some people in the general public who might distract their kids away from him, because they don't understand. Over time, more and more people are comfortable with Conlan now and have learned how to communicate with him effectively. I actually have noticed that it is often medical professionals who have the most trouble interacting with Conlan because there's a disconnect that there's nothing that they can do with him because he doesn't have a physical disability, it's a neurodiverse one. A lot of people think physical ones are easier because there's concrete ways to address specific things, like ramps, braille, and sign language. The more complex the ailment, the more people shy away or are unsure of how to engage because they don't want to do or say anything wrong, but if medical professionals don't have any services in place for these people it's detrimental to the individual, the family, and their support networks.

Having previously lived in a small community, there's nothing we experience here in the north that comes close to what we experienced before. We had to make the choice to relocate to Yellowknife for the sake of our children, which was hard, because we felt there was no stigma towards disability in Aklavik. We never had to beg for Conlan to be included there because he just was. In Yellowknife, it's always been a struggle and never-ending compromise for my son's dignity, for his human rights, for quality of life, a right to be educated, for adequate healthcare, employment, and citizenship.

I wish people believed Conlan wasn't less worthy than others. If he were viewed as equal to other people, we wouldn't be having this conversation, we wouldn't be able to find a plethora of people sharing their own narratives and we would not have to literally put this all written down so people will try to understand and maybe consider that it in decision-making.
I have all the same fears as any other parent, but of course my biggest one is what'll happen to Conlan after I'm gone, because we have such a strong connection since we're together 24/7. I also worry about my other kids looking after Conlan and the unique challenges and responsibilities that lay before them and their future families. I don't worry that he won't have a happy life after I'm gone, because I know he will, but because he can't always communicate, I worry he'll be grieving, and people might not know he's sad.

In a perfect world, I'd like to see the systemic barriers removed, a real effort to include and make things accessible, to educate people, and make all policies informed by people with disabilities. I refuse to accept people saying they don't treat people less differently or don't have embedded prejudices while they perpetuate exclusionary systems or approaches. People should live where they want to, with their supports, without automatically saying it's not feasible. We need to stop this us versus them mindset and keeping the status quo belief that you should be happy with the little you have already been given. People don't need to be managed anymore; we all just want to be supported.

For me, inclusion means equity; it doesn't mean we're all the same, it means being respected, having dignity, being together in the same place, and people desiring and wanting diverse people to be there. Inclusion means being a human being whose human rights are being respected.

My advice for parents is live and flourish in your child's strengths. Don't let others' comments, thoughts, and prognosis affect you, because your child is perfect just the way they are, it's the world that's imperfect. Don't be afraid to ask for help and don't be afraid to force things to change if they must. All I wanted is for my kids to be happy and make the world a better place, and I know every one of my kids has done that.

For younger parents, my advice is to be realistic, but don't shut down opportunities. Don't believe that you need to grieve when your child is given a diagnosis, because every single day we learn more about what people can do. Find ways that your child can be involved in the interests that they love in a way that is useful, productive, and will meet their own needs to feel fulfilled. Sometimes it means convincing a lot of people, and hopefully by the time the next generation turns 18, there's more diversity and realization that colour, gender, sexuality, religion, disability or and other personal characteristics don't define us.

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