Voices of Youth: Northern Narratives of Disability

Voices of Youth is a youth-driven project that explores the lived experiences of young people in the Northwest Territories who self-identify as being part of the disability community. Our project collects the narratives of young people in order to share authentic representations of the successes and challenges we face in our communities. Our stories have been compiled to showcase the resilience, strength and vibrancy of the disability community in the Northwest Territories. It is also our hope that these narratives serve as an outlet to better understand what it means to live with disability in the Northwest Territories, while creating space to critically examine the barriers that persist for us in our home communities.

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Who are you and what is your disability?

“Hi my name is Sasha Clouston I am 21. I live in Yellowknife. My disability is Cerebral Palsy [and] right-handed hemiplegia. My interests are mainly dancing in my room and just being me. I don’t really play sports but I was involved in Special Olympics bowling. I live with my mom, my grandmother [and] my two sisters. They have supported me throughout... they have done so much for me. I also have five dogs. Five dogs are nuts. I live in Yellowknife, Northwest Territories. I lived in Yellowknife until I was 9 and then I moved to England and then I came back when I was 17, so about 4 years I lived here now. When I was in England I went to the Duchess Community High School. When I moved back I went to St. Pat’s. I was a big part of Best Buddies and when I finished up there I worked at Home Hardware. During my schooling I worked at the NWT SPCA in Yellowknife. I also just finished up my job at the NWT Disabilities Council. I went to Old’s [College], which was amazing, met a lot of great people down there. In Old’s I studied the Transition to Employment Program. It’s a program where disabled people can learn how to budget, how to get a job and keep it, and basically learn how to live on our own.”

What have you brought to your community?

“What I feel like I’ve brought to this community is to show that I’m disabled, but I’m like anyone else and I’m strong. I’m a fighter because that’s how I was, my mom was a fighter and that’s where I get the mean streak from. With being disabled and living with this disability all my life I’ve been through some struggles. I know how it feels to be told “oh you can’t do this, you can’t do that because you’re disabled.” That really makes me angry to the point of no return.”

Why did you want to get involved in this project?

“I basically think that this project is going to help youth—especially disabled youth—get to know who they are as a person, as I have. Once we’re finished, people will start to understand where it comes from, who we are as disabled [people]. We’re not just disabled, we are strong.”
What does disability mean to you?

“Disability means that there’s certain restrictions but there’s not many. It means different abilities. It doesn’t mean that you can’t do something or you’re a failure. It means that you’re a strong enough. It means you have some restrictions but you have certain abilities. The thing is I feel like everyone is disabled in their own ways. Everyone can’t do everything and it’s taken me 21 years to realize that. People around the world don’t understand that. People think… they hear the word disabled, they automatically think that you’re not… you can’t do stuff.”

How do you feel about your disability and how has that changed over time?

“Back when I was younger, like a teenager (13 or 14) I thought that being disabled was… I’m not gonna lie, was a disease… was my own issue. I wouldn’t embrace it. It made me go down a very difficult road where being disabled meant I was an idiot. One of the main reasons I moved back from England was being put into college for a program for 7 years and all my mom could see was dollar signs in the people’s eyes who were interviewing me. I felt like being disabled meant that other people would get money and we would get nothing. Now, coming back from there, coming back from England and moving here has opened my eyes to so much. It opened my eyes to that you have to embrace it and you are strong as a person. Being disabled doesn’t have any effect on who you are as a person and as a human being. Yes, you live through the challenges but so does everybody else.”

What part of moving back to Yellowknife changed the perception you had of your disability?

“Just the people I met. The people I met in school and here and being around people that understood [and] that didn’t necessarily understand, but helped me through… just watching my sister grow up to being stronger as a person and my mom too. My family is the biggest one. There was a saying that my step-dad always used to tell me, “I can’t is a phrase, don’t use it.” I used to say, “I can’t” a lot.”

What challenges do you face in your community?

“Transport. The transport here is great yes, but it’s a lot of money. When I came back to Yellowknife, I used the YATS bus with my sister for two months and it cost my mom 100 bucks each month for the both of us. It’s way too much money. Like fifty bucks per person for a month? That’s kinda stretching it.”

Why is $50/month a barrier for people with disabilities?

“I do think they have a harder [time] paying $50 a month. I do think it’s harder for us, being disabled, to find jobs. I mean I met this woman on the [YATS] bus and she was saying that she can’t afford that… it’s ridiculous.”

What impact does inaccessible transport have on your life?

“I can’t get out anywhere. I have to either depend on my mom or depend on my friends or my grandmother. My grandmother has a lot of trouble remembering where to go. For example, I ask her to take me to work and I have to lead her everywhere. The other thing is my mom works nights so I can’t depend on her all the time, like no way.”
Do you face other barriers?

“Inclusion I feel is a big one because I don’t understand some of it that’s going on. I don’t understand the community events or some of it’s really hard or I don’t hear about them. I don’t understand where it is or how to get to it. For employment, in 2015 I was working through YKACL at [local business]. Before my contract ended, I was told there was a possibility of me getting a full time job but they turned around later and said “no”. They said that they couldn’t do it because of the fact that I was disabled. That makes zero sense. A lot of it has to do with, lots of the businesses don’t think they can afford to have disabled. We’re like everyone else, [but] we don’t look at the disabled like everyone else. They look at the disabled as “Oh they can’t do it, so they can’t work.” How in the hell are we meant to have, how in the hell are we meant to live in Yellowknife if we don’t have the money? If we don’t have any income coming in?”

What are the benefits of a business hiring a person with a disability?

“The benefits to hiring a person with a disability is that the people that come in will get to see that person in action and see like: “hey, this person does have a disability but this person can work and so maybe this person isn’t as bad... maybe I should get to know them””

What advice do you have for other youth with disabilities?

“My advice is don’t be pushed around. Don’t let them push you. Don’t let them tear you down. Be strong and see it will get you through. Have that support system, have your family, and if you don’t... find people who will support you and all that you are. Be who you want to be. Don’t let anyone tell you who you can and can’t be. Just be strong. Just be you and be happy.”
Can you introduce yourself?

“Well my name is Connor Beaton. I am 19 years old. For elementary school and middle school I went to Ecole St. Joseph School, where I ended up making a lot of friends and getting a little bit of support. For high school I went to Ecole St. Patrick High School, where really I began to shine, myself, as a person. I am currently diagnosed with Autism and everything, which if you look at me first hand you probably wouldn’t notice it as much, since it’s not as obvious as it is with some other people. It just means it’s a little harder for me to understand certain facts or just understand social qualities or just makes it a tiny bit more difficult for me to learn at school.”

How have you been involved in your community?

“Well I didn’t really start getting involved much in my community until I joined Special Olympics in grade six. It’s where I truly started to feel like I belonged because these were people who understood what I was going through, in a way, and it was just where I was allowed to go and have fun and just be myself without worrying about people ridiculing me because I was different. The first two [sports] I did were swimming and bowling- bowling was where I shined the most! [In high school] I went on the War History Trip, where we learned about the great two World Wars and everything- WWI and WWII and just learning about all about the history of what went down in there. When we went on the trip we visited a lot of great events and everything. I was in Food Rescue during my grade nine summer, going with delivery to help pick up food and everything. We ended up picking up food from Extra Foods and we delivered it some days, like I took a couple to homeless shelters.”

What does being involved in your community mean to you?

“It makes me feel not excluded in a way. I look at some of the people in my life and see all the amazing things they do... they give to their community and everything and just what they want to do in order to get experience to accomplish the goals they have in life. I thought I want to do that too just to prove to myself and other people that I am perfectly capable of accomplishing that kind of thing, so whenever the opportunity came and it was a good timing for me I volunteered as much as I could. I could make sure I could get the experience and just help make myself feel better about myself. I really learned about how much more I was capable of and how more capable I was of developing really good relationships with people I knew. Throughout elementary school, I [had] friends... but I never had a group of friends that I normally hang out with almost every week. It was kind of a lonely childhood for me. It was a bit easier in school but once I was outside school I spent most of my nights at home. Once I started high school-around grade nine-I developed a lot more good relationships with people and everything.”
What does disability mean to you? What does it mean to live with a disability?

“Disability is one of the hardest things to understand because [each] person is never truly the same when it comes to disability. Like take me with Autism, I’m pretty sure at first glance you probably wouldn’t guess it, like there are some people who just make it really obvious, but you shouldn’t judge them just because of what they were born with. You should just be happy that it’s what makes them unique and everything. They have their own unique way of dealing with the world and it’s just one of the best things you can have in life - just your own way of going through life.”

When did you realize you had a disability? How do you feel about it now?

“Well the first ten years of my life I didn’t realize I had one since when I was younger what I did for stress relief was I had an elastic band that I always twirl around my hands (sort of like a fidget spinner) and it just made things calm down or keep myself busier. I would say there’s not much of a difference now except I feel a lot less self-conscious when I flip [my string] outside in public. Sure some people stare but those are just random strangers that I probably will never see again. I don’t really care what they think because they don’t have any right to judge me since it’s just my way of interacting and being calm with the world.”

Do you find that’s it’s ever hard to try and explain your disability to people?

“It’s not really an issue for me. Like when people see me flicking my string on the streets they think... like I’m assuming their first thoughts are “oh yeah, look at that kid he’s all hyperactive or hyped up on coffee,” or like “oh my god, that kid’s probably a freak or something”. I just don’t let that stuff bother me because I would feel more bad about it if it was my own classmates or just people I grew up with or something, because those are people that I actually probably know. If it’s just random people you shouldn’t care what they think cause if you don’t interact with them, who cares? They’re just people who have that first impression. People make their first impression in the first three seconds of seeing you so like if it’s [a] bad impression, you have the opportunity— if you see them again— to prove to them how wrong they are. If you do have to explain [your disability], just try to explain it in a way they will understand [and] that will truly show how you work.”

What are your goals for the future? What does a good life mean for you?

“To me a good life means a successful career. [so] doing something I really enjoy or at least something I’d be satisfied with for the rest of my life, and my eventual goal is to have a family. I’m just concerned with whether or not if... since I have no idea if people can inherit disabilities from their parents... I’m just concerned like how difficult it will be for me and everything. Because even though I’m Autistic myself, there’s no guarantee if my future children have Autism, they’re gonna end up in the same way as me, but I’m willing to go through with it because as long as I have the support and the love I’m sure I’d be happy with it.”

What supports would you need to reach that?

“I would say someone checking up on me every now and then [to make] sure I’m following the same routine when it comes to paying bills, doing taxes and everything. To make sure that I’m just keeping everything in check and, job-wise, maybe the occasional check-up every once in a while to make sure [I’m] doing everything as well as I could.”
With the inconsistency of chronic illness, do you ever fear people will misinterpret your symptoms?

“Yeah, I get worried people will think my fatigue is laziness. I mean there’s a lot of factors. It’s not like Crohn’s is my entire personality. I know that there are other aspects that go into what makes me a person. I mean I try and balance it out and force myself to have as much energy so I can sort of counteract that.”

What advice do you have for youth living with disability?

“I would say this: just because you have a disability, don’t let it be your main identity or anything. Just because you have a disability doesn’t mean you can’t do all the stuff that other people can do. It may be more difficult but that just means you have to try harder to prove how wrong they can be when they first find out what you actually have. It may be difficult [but] it just means you have to work harder to push yourself to the limit, to prove to yourself that you can do the stuff that everyday people can do.”

When you think about your future do you have any fears or concerns?

“Honestly, one of my greatest fears in life is that society won’t truly accept people with disabilities. Like if I’m in a new workplace and if a lot of people don’t accept me, it’s just gonna make my life a living miserable. Life is good for me but it’s a lot because people have accepted me for who I am. I would say my worst fear is going to a new workplace that I know I would really enjoy and everything but none of my coworkers would actually want to hang out with me, show me the ropes and actually get to know me as a person. I fear that if I have kids with Autism they’re gonna go through the same kind of ridicule when they go to school. I was really socially awkward as a child, so I didn’t know how to come up to people and just make friends. Some people, they just came up to me and just asked if I want to play at the playground and I just accepted it right away ... as long as you have one person who accepts you, you should be fine. Having people who want to hang out with you [and] support you through life, it just makes all the difference in the world.”
Who are you?

“My name is Jacob Kudlak. I am 21 years old. I was born and raised in Yellowknife. I’ve been here all my life. I was born with Cerebral Palsy. My interests are playing guitar, fishing, reading and spending time with friends and family.”

How do you get involved in your community in Yellowknife?

“I volunteered for the Disabilities Council a few times. I was a member of Best Buddies at St. Pat’s for two years. It was a group to make new friends and spend time together. I was involved with Special Olympics for a few years too in bowling. I worked at the SPCA, the Disabilities Council and Computers for Schools and also Tamarak. In Old’s College I worked at Student Services.”

What has your community involvement meant to you?

“I feel like I meet new people and make new friends and feel proud of myself to be a part of something.”

What does living with a disability mean to you?

“Never being negative, always try and be positive throughout your life.”
What is something you’re proud of that you want people to know about you?

“I’m proud that I’ve completed school, so middle school, high school and college. I went to St. Joe’s for kindergarten to grade eight from 2002-2010. Then I attended St. Pat’s from 2010-2014 and Old’s College from 2015-2016. I took the Transitional Employment Program and I enjoyed it there.”

How did you feel when you were about to leave for college?

“I felt a bit nervous that I was going to miss Yellowknife a lot and my family. It was tough but I adjusted a few weeks after I started school.

I was nervous about being on my own and getting around on my own. It made it a lot of easier after making some friends and keeping myself busy - a lot of gaming and spending time with my friends.”

What challenges do you face in your community living with a disability?

“There was a few things that I couldn’t do that everyone else could do, so that was a bit difficult. I find it difficult always having to ask people for rides to get to places I want to go. Sometimes I wish I had my driver’s license.”

What impact would independence in transportation have for you?

“I would feel like I would have more freedom. I could go anywhere I want any time.”

What does a good life look like for you? What are your goals for the future?

“To find more work and live on my own and hopefully have my drivers license, probably in Yellowknife.”

What advice would you give to another young person living with a disability?

“If you live with a disability, don’t let it slow you down. Never give up on what you want to do.”
Who are you?

“I’m Justine and I went to St. Joe’s and St. Pat’s and then I went off to Fairview College and Grande Prairie College. I grew up in Yellowknife. I moved here when I was five from Halifax. I live with my family: my mom, my sister and my sister’s boyfriend. I am 21 and my disability is called non-verbal learning disability. I also have anxiety and OCD.”

What does your disability mean to you?

“The non-verbal learning disability, it really impacts how I see things and sometimes I have trouble communicating with people. Sometimes I get mixed up in what they say a lot. They say something and I may take it as a different way. I have a lot of trouble with directions and maps, so if I were to go to another town and look at the map I wouldn’t be able to figure out where I am in the city. I’d probably just get lost. It also affects my math and it kind of like affected me at school because I had to use a modified program at school. It was just easier for me to learn that way. I learn visually. For anxiety, I was diagnosed with severe anxiety and it really impacts when I have to go to work because I can’t work the full day. I have to work half the day because in the mornings my anxiety is the worst and usually I get really bad stomach aches and or I’ll like start shaking. It just prevents me from being social with people I don’t know. Like if I know them I’ll be fine with it but if I don’t know them I’ll just be really nervous. Sometimes just going to new places really freaks me out or with taking the bus. I had to get a respite worker to help me take the bus to get used to it.”

When was the first time you realized you had a disability? How do you feel now?

“I found out in grade three for my non-verbal learning disability. It was really stressful because sometimes I had to be put in a different class and transfer classes just to see what would fit better with my disability and if I needed an easier class to help. I would also be a little bit upset because I missed my friends at school as well, but I just got used to it and it became a part of me. I just slowly accepted that this is who I am and it’s okay to have a disability.”

I’m more comfortable. I mean I still have times where I feel like I can’t do anything and I am kind of worthless and stuff. Sometimes I still feel like that at times, but I have people to help me to get me back on my feet if I’m having those bad days. I’ve just go to remember that those are just bad days but having a disability is okay. You can still enjoy life even if you are different and people treat you different. I find people have been so helpful with like helping me out with my disability and helping me realize that just because I’m different it doesn’t mean that I can’t do anything. My family has been the most helpful, especially when I was in college.”

Do you think people’s idea of disability is positive or negative, in general?

“I think it can be both. It can be both positive and negative because like sometimes people don’t really understand people with disabilities. They feel like they have to treat them (people with disabilities) differently in order to fit their needs. Sometimes it can be positive because like sometimes the help is good that we get from other people when they treat you like a human and not just like a random thing... and they just kind of like treat you like a normal human being. Just because I have a disability, you don’t have to change the way you act towards me.”
With the inconsistency of chronic illness, do you ever fear people will misinterpret your symptoms?

"Oh yeah, I get worried people will think my fatigue is laziness. I mean there’s a lot of factors. It’s not like Crohn’s is my entire personality. I know that there are other aspects that go into what makes me a person. I mean I try and balance it out and force myself to have as much energy so I can sort of counteract that."

How have you been involved in your community?

"I did drama club at St. Pat’s for the full four years I was there. It was really fun because I also met a lot of friends there and they’ve been a part of my life since I started drama club. Being in drama helped me kind of get out of my comfort zone and used to actually talking to people on stage and in front of people. I’ve also done a lot of volunteer work. I work at Old Town Glassworks and I help out with the designing of glasses and with the sandblasting. I also help organize in the back and help do errands if they need any extra supplies. I also did volunteering at NACC and I helped out in the offices there. I did some organizing there and I got taught how to use the ticket system. I just really enjoy like working or volunteering and figuring out what I want to do when I’m older."

Why was it important to be able to be part of your community?

"I think it was very important because if I didn’t take part in the community I would have just been at home and been very bored all the time. It also just helps me feel more comfortable, like with my disability and with my anxiety to kind of help me figure out what I want to do when I’m older. Also it helps me get out of comfort zone and help other people in the community."

What helped you be successful?

"Mainly my support system. Like counselors at school, they were very helpful. Also my mom, she does a lot of things for me. She’s really helpful with my disability and if I need something we try and see if we can get it together and just work hard for it. I’ve also had respite workers this past year and they’ve also been so helpful. They’ve been helping me take the bus, getting me out of the house more. For a while there I was having a few of those bad days where I didn’t want to leave the house and stuff but then like once my mom got me a respite worker, they actually took me places. I was feeling really happy and upbeat and they just lifted my spirits up a lot."

What program did you take at Fairview College? What leadership role did you take on there?

"I went to Fairview College to learn different skills of living by myself. I was the president of the class (Transitional Vocational Program- TVP) and we had meetings every week in class and we talked about things we would like to fix or help make the program better. Also, that was the last year of the TVP in Fairview and so that was a really big thing. Me and my friend decided to come up with a petition and we got a lot of people in the town to sign and to try and save the TVP. I also got Rachel Notley and this other girl from the NDP [who] really helped with the program and trying to get it back. I also got a leadership certificate for like being a role model for the program and for the city for helping try and bring back the program."

What did that feel like?

"It felt really good. I didn’t actually think I could ever do something like that, but when I feel so passionate about something like the program… all I felt is I just needed the program back and people just need to opportunity to get the same like experience as I did while I was there. It helped me out a lot in the future and I still use some of the skills I learned there."

Meeting other students with disabilities, what was that like?

"It really impacted me because it basically made me feel like I was normal. Just being able to be successful through a school even when you have a disability and seeing all these other kids with disabilities as well. It’s just amazing to see what we can do when we put our mind to things."
What does a good life look like for you?

“Right now I’m working towards getting my own apartment or possibly living in one of the homes with Abe Miller Centre. Just being happy with myself and accepting my disability as it is and finding things that I love to do."

What could be done to improve the lives of people with disabilities?

“I would say if they had a skill program through high school, skills like definitely budgeting and also life skills. Important skills like the stuff you do at home: cleaning skills, cooking skills, and even maybe skills that could help you get through classes [and] strategies to help with your disability and what you could do if one day you’re having a really bad day. Also maybe to have like a hang out spot for people with disabilities to meet other people with disabilities to meet and tell them each other’s story about what they’ve done. It can help them to think that they can be successful as well.”

What advice do you have for youth with disabilities in the NWT?

“I would say always ask for help. Don’t be afraid to ask for help, even if you feel scared to. It’s always worth it in the end if you ask for help.”
Can you introduce yourself and Conlan? Why are you speaking on behalf of Conlan?

“My name is Kyle McKee and I have a brother with a disability. We were born in Hamilton, Ontario and we lived in Hamilton until we were about the age of 11. My brother, Conlan, and I were both the same because we’re twins. Then we moved up to Aklavik and we spent a few years there and then we came back for high school to Yellowknife. Now I’m off to university in Alberta and Conlan still lives in Yellowknife. Conlan has Autism. Conlan’s disability means that Conlan has certain social and cognitive barriers that prevent him from being able to do some of the things that other people are able to do very easily or he just has to try a little bit harder to do many things we might take for granted.

So Conlan is my twin brother and, as I said, he has Autism. So it’s... it would be difficult for him to communicate the same things that I can communicate and that’s why I’m in the position speaking for him. Conlan has very limited expressive communication. Because he’s my twin brother, I’ve experienced a lot of the things that he’s experienced right by his side- all of his siblings have. We have a pretty good knowledge of how Conlan behaves and kinda the challenges and barriers that he’s faced and his community involvement and basically how he lives his everyday life.”

Who is Conlan?

“So first off I’d probably say that Conlan’s pretty energetic. He likes to jump around... he’s pretty active. He likes sports a lot. He does Special Olympics outside of his school and work. So he does bowling weekly, he does swimming, he does speed skating in the winter, he likes to go biking and for lots and lots and lots of walks. Conlan’s a very caring and empathetic person, which you’ll see if someone gets hurt. He’s ready to jump up and make sure that you’re okay. We all learned that in the same way... we all grew up in an environment where that was something that was valued and taught. He’s smart, especially when things are in routines. He likes to get a routine and get his work done. He’s very efficient when he knows what he’s doing. It just might take him a little bit to get used to a routine but that’s the kind of stuff he likes to do.”

What things do you think Conlan is proud of that he’d want people to know about him?

“ I think what he’s most proud of, as a person, is probably his work. He gets really excited when you talk about his jobs. He has multiple jobs: he works over at Buffalo [Airways], which he’s really excited about and I’m sure that’s something that he’s really proud of because that’s something he really looked up to and liked for a long time. He really liked going to the airport watching the planes when we were kids, but he was especially enthusiastic about the scene over at Buffalo with all the old airplanes. They even have the TV show and stuff and Conlan really liked it. He really liked driving out to the airport and watching the old planes take off and then he finally got a job there and that was really exciting for all of us. I think especially for Conlan because not only does he get to go watch those planes everyday but he’s also a part of the team and gets to wear all the gear. He’s got his little station set up there with his name tag and stuff, so I think that would probably be something that he’s more proud of. He [also] works over at Canadian Tire and he’s worked at the Fieldhouse and Home Hardware. I think he’s really proud of that. Those are the kind of things that I feel like gives someone- especially if they haven’t had a chance to work before- gives them a sense of acceptance and like normalcy. They become just like everyone else that’s going to work everyday, especially with us going off to university and stuff. He definitely realizes that we go off to university and he stays here and he understands that. He’s got things to do during the day to not only keep him busy but something that he actually likes and is passionate about, which is good.”
How has having a sibling with a complex disability impacted your life?

“I think it’s definitely made all of us a little more open-minded, accepting, understanding [and] empathetic. You are more careful to reserve judgment. Like when you understand what the family of a person with a disability has to go through you’re... I feel like you’re less likely to judge other people. Even if they don’t have a person with a disability in their family, you might not know what’s really going on beyond what’s at the face of someone. You understand that there are things that can impact people largely.”

Do you remember any challenges?

“I guess when you’re a little kid... the first thing you experience is when there’s another kid pointing and laughing or something like that. You get really frustrated and you’re just a little kid and so you don’t know how to deal with it. You end up pushing the other kid, or getting mad, or maybe that’s not how you deal with it so you go get anxious and mad and sad or you stand up for them... everyone has their own way of coping with it. That would be a challenge that every child that has a sibling with a disability would certainly face. There’s no getting around that. I guess there are challenges when you get a little bit older and you’re getting involved in these new things. Like when I go to hockey or something like that and Conlan is at home and you feel guilty for leaving and not bringing your sibling because they’re sitting at home. That’s one thing you might face.”

What fears do families supporting a person with a complex disability have?

“Support... if you have to bring in some kind of support worker. Well there’s [one] option of bringing them into some kind of community services during the day and then the fear is if they’re doing something actually meaningful... that they’re doing something during the day that they’re proud of. If someone goes to work and they do a good job and they’re at a place they like to be at with nice people, that’s the ideal situation. The fear is that you bring them to a community facility and they’re sitting down and colouring all day, or not doing anything meaningful, or the workers are not very engaging at all and they don’t care about people. That would be a fear, that they’re going out every day and doing something that’s not meaningful and they’re not getting the quality of life that they deserve.”

How do you think isolation influences young people with complex disabilities?

“‘There’s always gonna be that sense of isolation because at the end of the day the siblings of a person with a disability are living their own life. [There’s] gonna be a bit of a distance- no matter how hard you try- that’s gonna build between you and your family members in general, so it’s bound to happen between you and the sibling with a disability. You try to limit that because you know that you want to be there for them, but there’s a bit of isolation and that’s where it begins- when your family starts to live their own lives that are slightly separated. For Conlan, when we [siblings] go off to school [he’s] left to just socialize more with our parents. He has the stuff after school and that, but we’re not there. That’s the first wave... the first hit of isolation. In the community too, like he still goes to school but a lot of the kids that he liked to interact with, like our friends that interacted with him graduated and stuff so they’re kind of moving away. It’s also the community isolating people with disabilities and that would be reflected in a lack of services for people with disabilities to push them away. Conlan is very lucky to have the jobs that he goes to through school, but a lot of people aren’t given all those opportunities. People are left to sit at home all day and do nothing, or they’re put in a group home or put into some kind of care during the day where they’re left to do more meaningless things. Even though there’s a worker there, they’re alone in the sense that it’s not people that they know and they’re just doing things that... it depends on the place... but they’re left to do these meaningless tasks. They would be pushed away from society in the sense that they’re not able to contribute to society. If you’re sitting inside and limiting someone who you know is capable of more than that to colour all day, then they’re not allowed to contribute to society and meet all these people. They’re isolated from the active community.”
What is something you think could be done to improve Conlan’s quality of life?

“Well I think Conlan is lucky now in the sense that he has a decent amount of social interaction with the things he participates in. In the summer it’s a little less because most of the things finish up but in terms of community activities I think just more social interactions would be good, that are separated from just the sport or going and doing something… just more interaction with peers. As people with disabilities, like Conlan, get older and they finish school and try and go get jobs and that kind of thing, the time seems to be more spent more directly with the family. When we [siblings] go to school, it’s especially more with his parents who are much older. It’s not the same thing as a social interaction with your peers. Increasing the amount of interaction with peers would be good. In terms of getting a job, he has the few jobs he goes to with the school but it would be good if he was able to go to get some kind of full time position somewhere that he really liked. That’s what everyone wants.”

Why do you think it’s important for all the people that Conlan has a presence in the community?

“So I guess when someone meets Conlan they’re… I think the way a lot of people could benefit [is] by creating a new outlook. Some more close-minded people or people without any experience with people with disabilities would look at Conlan and maybe eliminate some of the stigma attached to people with Autism or disabilities in general. Conlan is very kind, very energetic. [It’s] very easy to be around Conlan and you want to be around Conlan because he’s always happy about what’s going on and what he’s doing. Conlan could go out there and influence them in a positive way and show them that people with disabilities do have personalities, are happy with what they’re doing, do have emotions, do have passions for things and you can really see that in Conlan.”

What advice do you have for siblings and families?

“Think ahead. When you’re not thinking about the big picture, it can come up faster than you think. Then you’re not sure what you’re gonna do when your sibling graduates high school, for example, or how they’re gonna get a job or get the social interactions that they need so they can achieve their full potential and be an active member of society. I think these things are important to think about and be cognizant of so you can be actively searching for the answers to these questions because they will come up. It’s easier when you’re prepared.”
Who are you?

“My name is Jenna Aitken. I am 22 years old. I’m High Functioning Autistic. I moved to Hay River, NWT when I was 5 years old. I graduated from High School in Hay River then I did three years of college in Alberta at GPRC (Grande Prairie Regional College), got educational assistant diploma and Level One Daycare certification. I’m currently looking for work. Some of my interests are: reading, cooking, swimming and anime.”

What was your community involvement like in Hay River and now in Grande Prairie?

“I don’t have a lot to say about Hay River because I was never really felt a part of it that much because I was out-casted so much, but with Grande Prairie you know there’s so much more to do. I have friends in the city so I hang out with them a lot. In Grande Prairie we also volunteered at a children’s festival and I did some work experience, which is volunteering at the schools. I also volunteer at a Mission Thrift Store in Grande Prairie.”

You mentioned that you didn’t feel part of the community in Hay River, what did it feel like to feel isolated in your community?

“Depressing, sad, frustration, anger, confusion…that kind of stuff”

What do you think the attitudes people have about people with disabilities in Hay River?

“They can’t do anything, there’s something wrong with them, they’re useless, they can’t and they’re not smart”

Why do you think people aren’t motivated to support people with disabilities?

“One thing is maybe they don’t care, it’s not their problem, why do we bother helping people that aren’t going to go anywhere in life? I mean I heard a lot of negative attitude about that, that particular sentence I just said: “they’re not going to go anywhere in life, so why bother?””
Was it hard to come to the realization that you were different from other people?

“Well I mean I always kinda noticed growing up when I was younger that there was something different about me... I mean because I couldn’t talk a lot like the other kids and I wasn’t like the other kids. There was always a difference in how I spoke and how I acted. It wasn’t a big difference between me and the kids but a lot of emotional, my intelligence, how I could... how I learned. I understood a lot about the world at a really young age and a lot about realities so I mean that was different so a lot of that kind of stuff. And then some things like my anxiety. I mean it was tough when I learned I was different. I always [was] wondering why I had trouble making friends and so as I got older it was like: “oh like what’s wrong with me?” That was what probably the worst part of it was. If you’re not liked, if you’re not popular, if you’re not super sociable or if you don’t party, you don’t get treated very nicely.”

How do you think how you feel about your disability has changed since you left Hay River?

“Oh, it’s changed severely. In high school a lot of it was like: “What’s wrong with me?” “Why am I being treated like this?” so a lot of those kinds of feelings. The biggest change was in Fairview College that was: “hey, wait a minute, there’s nothing wrong with me. There’s nothing wrong with me... I’m just different. It’s just different.” There’s these people around me and they’re in my class and they’re different just like me, so there’s nothing wrong with me.” So I guess that was the biggest change and realization. And then after I got out of Fairview, you know I was better and stronger in emotion and my self-esteem was a lot better.”

What things helped you be successful?

“My parents both had a background in special education and both of them worked with the NWT Disabilities Council... but even then they had to fight for a lot of my services. Like getting me tested for High Functioning Autism; that was a battle on it’s own. Just so many battles for supports. I did have a little bit of support in high school but that was only because certain teachers who wanted to help me pushed for that. In general, the support staff in school was stretched so thinly. I also had some outside help from an early age from a woman who came who helped me and another boy in school.”

What is it like for families who don’t have parents with that kind of expertise?

“They don’t even have the ability to fight. So yeah, I would say it’s a big problem. They would probably just go without; they would just try and find a way to cope with it, which can sometimes be impossible completely. There’s little to no support.”
What do you think a good life for a person with a disability looks like?

“Like I have a friend, a couple of my friends actually have disabilities in Grande Prairie here. Some people are on supports, so they’re on like an Alberta program so they have some income to pay their rent etc. So I mean that’s good that they have something, but they also need something to do. Like whether they are on benefits and they might actually work and make a little bit of money or they’re just on benefits or they work full time, they need something to do. I mean right now me and my friends are going through this. We’re just looking for work but we’re driving ourselves crazy because we’re bored during the day. Like so they need… there needs to be something to do. Like even if they’re volunteering through the day. That’s one thing in Hay River that there was never a lot of, not a lot of like safe or good volunteering or work opportunities for people with disabilities. Either it wasn’t a safe place for a person to be, as a person with a disability, or there wasn’t anywhere for a person with a disability. Well I mean, what does a person do?”

Do you think that not being able to have those opportunities might drive people with disabilities out of the Northwest Territories, out of their communities?

“I think so, absolutely. Actually in TVP (Transitional Vocational Program, Fairview College) there was some people from different provinces who moved to Alberta just because there’s more opportunities here. There’s more there’s a few more disability supports in Alberta. So yeah, I think it’s gonna drive people with disabilities out if they can leave, but some aren’t able to.”

What advice would you like to give to the other youth?

“Do not give up. There’s been challenges, certainly, but just don’t give up. If you want something and you wanna get somewhere, fight for it. Keep trying. I’m not going to say it’s an easy battle, because it’s a bloody hard battle, but I am glad I didn’t give up in high school.”
Who are you and what is your illness?

“My name is Patrick and I was born in Toronto. When I was 6 years old I moved to Nunavut, 7 years old moved to Yellowknife and been here ever since. I’m going to Grant McEwan University. I sort of went through a bunch of different schools before then. I’m doing graphic design- gonna get a Bachelor’s in Design- hoping to do a lot of work with non-profits in the future. I have Crohn’s disease. Basically it’s a type of inflammatory bowel disease. It’s a lot worse for a lot of other people. I think I have a fairly mild version of it, but it can get to the point where it can affect my regular day-to-day life pretty negatively.”

What was it like to receive a diagnosis of chronic illness?

“I mean honestly I was pretty cheery at the hospital. I didn’t care. I was kind of like “this is a chronic illness, like I had it before so obviously nothing’s gonna change except for things getting better.” I had the symptoms of it: constant low energy, the flare-ups, and the stuff that comes with it. I just kind of didn’t have an explanation for it. [Once I got my diagnosis] I just thought, “oh, this is how my body works... this is who I am.” Once I had a label for it, I was kind of like, “finally, this makes sense now.” I was able to take more effective steps to combat it after that.”

What is it like for you to come to terms with your limitations?

“For dealing with my limitations ... I don’t know... I try not to let Crohn’s be like my personality or anything like that. It can get to the point where it’s so all-consuming, like I’m in bed all day or something like that because I’m really in pain. I want to be outside of that.

I know that I can’t stress myself out too much because stress is another thing that triggers a lot of physical pain. I mean think it’s something I’m doing currently- trying to work in a way that I work, but I don’t work too hard because that’s just the way it is. I can’t wear myself out too much... as much as I hate to say it. I still am trying to figure that out to an extent. It’s just about creating systems for myself in which I don’t get too stressed out.”

How do you think a chronic illness like Crohn’s compares to a more consistent/stable disability?

“I think [that] sort of disability would contrast with mine in the sense that [it] is sort of more focused on like: “These (specific challenges) are the things that you’re gonna not be able to do. You’re not gonna excel at these things as much and that’s just it.” For mine it effects just like my daily sort of functioning in a sense. It’s like, if I get a flare up or something, it’s gonna ruin my whole day sometimes.”
How do you identify with disability as a person living with chronic illness?

“I don’t identify with it. I don’t identify what I have as a disability, I think. I kind of view it as almost just another aspect of myself. Maybe it is relevant to... I mean it is. It is a disabling thing it’s just like I don’t know... I guess I never really connected it that way. I don’t know how other people are with chronic illness. I know there’s a really strong Crohn’s community as there is for all kinds of different illnesses and disabilities and stuff like that. Seeing those people online, it’s been very supportive for me. I guess I never really saw it as a disability... like that word... because I kind of view disability like... I have a wheelchair in my mind, a person with Down Syndrome in my mind, and I guess I’m not those things exactly.”

How does that impact when you disclose your illness?

“I remember like when I went to college. They sort of asked me in person “are there any disabilities or supports you need?” and I was kind of like “nope”. It’s because it’s the sort of thing I guess I just have to power through and figure out for myself because the side effects that come from it are things like I get tired or I get worn out. Plus it’s just, you know, it’s kind of gross. People don’t necessarily know what Crohn’s disease is right away when you’re talking about it but it is the intestines. I mean I hate talking about that part of it. I kind of avoid that side of it.”

What do you think that society’s general attitude towards disability/ chronic illness is?

“I mean I feel like there’s a lot of acceptance for people with disabilities, at least in the abstract sense. People are like “oh obviously people with severe disabilities they need help so let’s give them the help they need” but it’s not necessarily [in] a proactive sort of way, I think. I think a lot of people are still very uncomfortable and still shun people with a disability that’s visible.”

What advice would you want to give to youth living with chronic illness?

“Never be ashamed of who you are. Never be ashamed of being different. You just can’t let that get to you. If there’s a stigma against you, you have to know that you have certain limitations and you have to know you’re not a bad person. You just can’t be ashamed of who you are because that’s not gonna get you anywhere.”
Who are you?

“My name is Alysson McKee. I live in the Northwest Territories, in Yellowknife. I’m currently going to school at University of Alberta for psychology. I think my main component of community involvement would have been when I was part of the drama club at St. Pat’s. I’ve always been interested in drama and musical theatre. At this point I feel like I really don’t have access to those things because I’m transient in and out of Yellowknife and Edmonton for school, so what I do is I write and I do visual art. I would like to do drama again.”

Why did you want to get involved in this project?

“The reason I wanted to participate in the project is because I saw other people do it and saw that there was no representation yet of mental illness as a component of disability and I guess I wanted to share my piece. I hope this can help with understanding, because my biggest issue is that I don’t have that platform to explain myself.”

How would you describe your experience with mental illness?

“It’s difficult to talk on and that’s because it’s cyclical. My experience is a lot of depressive episodes and intermittent phases of a kind of mania and minor psychosis. It’s not an out of body experience but it’s kind of a loss of control or a loss of the feeling that it’s necessary to control myself.”

What do you think the relationship between mental illness and disability is?

“I think that it’s certainly different than every other facet of disability [but] can be disabling. It causes me challenges in my life that are difficult for me to explain and difficult for other people to understand. I know there’s multiple different kinds of mental illness that you can experience, but in my experience I feel as though it’s a disadvantage for me both in a work and also in social interactions.”

Why do you think society generally separates disability and mental illness?

“I think primarily it’s quite invisible and it’s invisible more so even than a cognitive disability. I think for people with mental illness it’s separated partially because we separate ourselves, which is one of the reasons I wanted to do this. If you don’t acknowledge it as being disabling, then you don’t acknowledge it altogether.”
What impact do you think invisibility of mental illness has on whether or not people disclose it as disabling?

“I’ve never felt comfortable disclosing my mental illness in a format that wasn’t for the purpose of humour, or just in passing. I feel that if I were to disclose my mental illness as a reason for something or as a means to substantiate a difficulty I was having, in a workplace or school or anything along those lines, I would not be believed and it would only serve to damage me. We’re at a point where we’re acknowledging that mental illness is something that needs to be addressed but I find that it’s a matter of convenience whether we actually accommodate you. For me, it’s frustrating because I find that people are supportive in a convenient way and that’s why I don’t like bringing it up. It serves to isolate, ultimately.”

What do you think the relationship between mental illness and isolation is?

“I am forced to act and behave in certain ways that are different from my normal and that don’t seem authentic to me. The only time I feel like I can really be myself is when I’m alone, so it’s isolating.”

Do you think there is any sense of community of people with mental illness in the NWT?

“Well I do think we find each other [but] as far as a community goes, I don’t think so. The biggest community of people with mental illness that I’ve ever encountered was the high school drama club. I think that the means by which we cope, many of us with mental illness, is through the arts, so it really comes as no surprise that the people I’ve encountered in the various clubs and groups I’ve been a part of [in the arts] have been dealing with their own mental illness. I mean our brain chemistry is misaligned, but it’s misaligned in similar ways, so we find each other through art. Art is this exaggerated expression where we can do these things that feel authentic to us.”

What advice would you want to give to youth?

“You are under no obligation to be the person you were, not even a second ago.”
Who are you and what disability do you live with?

“I’m Harrison. I was born and raised in Yellowknife. I’m currently going to McEwan University and getting a Bachelor’s Degree in Honours Political Science. I have dysgraphia and dyscalculia. Basically what that means is that I have trouble writing and spelling, kind of like dyslexia but with fine motor control. As well, the dyscalculia means I have trouble processing numbers sometimes and it takes me a little bit longer to do any mental activities with numbers. So that kind of does affect my regular day-to-day life. I definitely need to do some extra things with that. It takes me a little bit longer and any really any math-intensive activity might take me a little bit longer. I have ADD, so that’s also another major factor that affects my day-to-day life.”

How has your perception of your disability changed over time?

“I mean of course when I was younger I didn’t like standing out, right? When I was in elementary school I’d have scribes and stuff so I’d have to leave when people were doing tests or things like that. I’d be the odd one out by having to leave and do the test elsewhere and no kid wants to be the odd one out. I was ashamed of it... well not ashamed, but I didn’t want people to know as much when I was younger, but as I grew up and in university I don’t care, I’ll tell people what I have. As I grew up and matured I understood this is part of my life and I let people know if they want to know.”

What does invisible disability mean to you?

“I’d say an invisible disability is like one where when you walk up and start talking to someone, you might not notice it right away. Someone might notice that I have a stutter but someone might think it’s something else. They wouldn’t know that I can’t write very well or I have trouble with numbers. They would just think of something else. I would say it’s when something’s not overt; it’s more covert.”

Do you ever have the concern that your limitations may be misunderstood because your disability is invisible?

“Well like my stutter comes along with my dysgraphia believe it or not and the problem is that some people when I meet them they assume that I’m nervous or something, so I have to describe that it’s because of my disability. [Another example is] if someone sees that I’m bad at spelling or my bad writing they would probably just say like “I can’t believe you spelt that wrong” it’s like I have to say “well this is why” or I blow it off like if I think it’s a minor thing, but it definitely can affect you because people assume that there’s no reason for it. When people assume that you’re just like everyone else then it comes like more of a shock to people when you say something is because you have a disability... just trying to explain to them that it may not seem like it, but it’s not just because I’m lazy or something. It’s like trying to explain to them that you’re just as smart as them it’s just that I you have a different variety of skills that I can use.

People say to me: “Why don’t you just study math more?” “Why don’t you just work harder on your writing?” I’m pretty sure people say that if they don’t understand that it’s a real limitation. Yeah, I might be able to do it but I would have to put in an extreme amount of effort compared to a person who say is just bad at math because they didn’t study it that much. It’s more of an inherent blocker that you kind of really have to overcome. It’s like having to climb a wall instead of just having to trudge through some mud type thing.”
How do you think invisible disability compares to visible disability in terms of attitudes and challenges?

“I’ll be honest there is definitely a hierarchy of it. There’s people, like for me, [who] you wouldn’t even notice, so I’m accepted a lot more than say someone who can’t communicate because of their disability or they have trouble being part of society because they have a very acute disability. I’ve seen people with disabilities and, since they can’t fit in socially, they get shunned from society. People don’t really want to be friends with them [and] don’t really want to get to know them because it kind of breaks social norms. If your disability makes you act differently than what’s socially acceptable then people won’t want to interact with you and then it’s harder for you to adapt and integrate into ‘normal society’. I think there’s definitely a hierarchy built mainly on social norms and acceptances.”

What could be done to improve the lives of people living with disabilities in the NWT?

“Get support. That’s the main thing. If you need support do your best to get it. Like I know in some places, like in the communities, it’s harder to get the level of support you need. It’s hard enough to get food in some places, [so] it would be even harder to get a scribe or some types of learning aides. I mean [we] mostly try and throw money at the problem but half the time that doesn’t even work, so it’s trying to build up the infrastructure that’s needed. There needs to be a better foundation of disability support. I mean it’s extremely hard because everywhere is so isolated here expect for Yellowknife. We need better infrastructure but even the landscape itself and locations can make that an issue... but try and get the support you need. If a person with a disability needs a support to excel then they should get that.”

What advice would you want to give to youth living with disability?

“I’d say: accept it. Don’t try and fit in because you’re different already, so just accept it as a part of you. Learn about it and live your life with that. If you have trouble accepting it, like say you just found out about it and you’re angry about yourself for it, don’t be like that because you’re living with it your whole life and there’s different ways you can learn to negate it or learn to live with it. I’d say accept it and do what you can and live your life and try and be successful. There’s no point in getting down about it [because] there’s always support available, even here. Unless you accept it and look for support, your life will just be that much harder. Do what you can. Try and find what works for you. Just keep trying.”
Who are you? What kinds of things have you been involved in that you are proud of?

“Hi my name is Carly Sayers. I’m from Aklavik, NWT. I [started] Moose Kerr School in 1997. I enjoy going to school because it gives you so many opportunities to learn new things everyday. I usually got involved with sports, you know like sports championships... like going out to other communities to do try-outs and all. Mostly, my interest was in soccer. I [also] go out to events and help out. You know, the Canada Day, Aboriginal Day [and] Mother’s Day celebrations. There’s a lot of things. I recently won two scholarships: Fred Carmichael Scholarship and ATCO Scholarship. I did work experience at Northern and Old Folk’s Home and the challenges were pretty tough working at those two places. You have to know exactly what you’re supposed to be doing and you have to be careful with the Elders too. [At the Old Folk’s home I did] mostly cleaning and helped with the Elders getting what they need. I had to help whoever was working there.”

What disability do you live with?

“I have FASD: Fetal Alcohol Spectrum Disorder.”

What does that mean to you?

“It doesn’t define me. It means nothing. Our disability is nothing but a challenge. They tend to stay home and do nothing for themselves just because they have a learning disability or a disability that makes them unimportant. Once they go out, get the education and get what they need, they realize that they can do a lot more than they can think of.”

What do you think disability means to you overall? What does it mean to have a disability?

“It means you have more challenges in your life than you ever think. People without disabilities look at us and think “oh, she’s an idiot” or “oh, he’s impaired” or anyone with disabilities they judge quickly without realizing there’s more to us than just that; we’re regular people too.”

What are some of the challenges you had living in Aklavik with a disability?

“Being judged for [and] getting picked on because I slightly have a speech impediment. That doesn’t mean that I’m not a regular person... that doesn’t mean I’m not a person at all. It just means I have more challenges in my life now.”

How did it feel to get picked on?

“A awful. People were shaming me for what I really am. I actually use those hurtful comments, words, teasing as a strength instead of a weakness. I am proud of myself now.”
What does a good life look like for you? What are your goals for the future?

“Now that I think of it, mostly just living on my own and keep surpassing my limitation, because there will always be new things that I have no idea of.”

Why is it important to you that you are able to have a job and live by yourself?

“Well most people [in my community], they finish high school and they stay home for the rest of their lives. They do nothing for themselves and it’s important to be on your own for a while. You never know, our parents may not be able to support us as long as they did and sometimes we need to leave the nest and create our own nest.”

What do you think could be holding people with FASD back?

“Well the bullying and negativity is one huge impact on that part. People take one look at how they talk and how they move and they think they can’t do anything for themselves. It’s tough to manage with that disability with the negative comments and all the bullying. Believe or not, people thought I was stupid because I have this disability. People thought I would never make it far in life. Sure I had harder time riding a bike until I was like 13 and sure I hated math in high school because it was confusing, [but] all the negative comments surrounding me made it a lot harder to learn than ever.”

How did it feel to leave your community and realize you could be successful?

“I felt amazing. I felt there was like new life in me that I never experienced. We never experience new life until we move out of our own communities and start something new. I felt appreciated [from] being supported in many different ways.”

What piece of advice would you give to youth in small communities?

“Try something new. Get over those fears. You never really experience life until you experience something new every day. Here it’s like the same old thing. Home will always be home. You can go out experience something new for a change and come back to your family and still remain the same person but with new skills and new life in you.”

What do you want youth living with disabilities to know?

“They have new life that needs to be experienced. They need to keep surpassing their limitation. Forget about the hateful comments; they just bring you down for no reason. Do not give them the satisfaction of what they want you to be. People will never notice you until you do something amazing in your life. Make a living out of yourself. Don’t just stay home in gloom. Suicide is not an answer as well. Just keep living and do your best.”
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