

Video title: Tamara Chevrier, Parent Experience-Let the Rivers Flow

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Kathryn: So, hello everyone and welcome to an additional presentation that we have for the Let the Rivers Flow gathering which, took place at the beginning of November. We're come to you a few weeks later with a new presenter who was unable to attend that day so, we're very pleased to have with us today, Tamara Chevrier from Temiskaming First Nation and she and Tamara is here as Lily's mom. So, we really look forward to hearing Tamara and Lily's story so, Tamara, over to you.

Tamara: Hi everyone, my name is Tamara Chevrier I'm from Temiskaming First Nation. I'm an Algonquin Indigenous person from Canada. So, I'm going to share a little bit about my family and our story. So, as you can see in the photos below here this my family. There's my partner Wesley, myself, my daughter Lily, and my son Thomas. So, hello my name is Tamara, this is my partner, Wesley. We are the parents to children with special needs. My daughter Lily was born with Down Syndrome and my son Thomas was diagnosed in 2020 with autism spectrum disorder. We are Algonquin and we live in the community of Temiskaming First Nation. Our community is located on the border of Ontario and Quebec. My partner is a construction worker in our community and I'm a stay-at-home mom. I'm excited to be here to share my story with you and our experiences and let's keep going. So, um, we were just a small family of three and at the time my partner and I were separated when I found out that I was pregnant with our daughter Lily. So, during my pregnancy with Lily I had many issues like high blood pressure, around 12 weeks I was spotting um, so from then it just escalated. High blood pressure, well it's hard to really keep that down when you have another toddler running around the house. Um, so it was very busy and very overwhelming at times. Later on, through my pregnancy I was diagnosed with preeclampsia and I had to try to keep my stress level down the best that I could, which was very difficult [laughs] and I was unable to do at times. So, the doctors had me on non-stress tests so every- leading up to the preg- the birth of my daughter I had maybe I was going for two, three weeks before I had her I was going in almost every other day for a non-stress test for monitoring, that type of thing. So, on October 4th [sighs] it was a very stressful, busy day. I started my morning getting my son ready for school and then I began to get ready for my doctor's appointment because we had to go in for a check-up. So, when I got to my doctor's appointment, we had done previous ultrasounds and such, monitoring Lily just to make sure everything was okay. Um, so on the Friday before- I had done an ultrasound then-and it- they [internet froze]- a hole in the sac where fluid was leaking [internet froze] for a c-section, but of course we just live in a small little town so our hospital was not really equipped considering that I was only about so, I believe I was about 20 [pauses] no, 35 weeks, 34 weeks along at that point but Lily wasn't measuring

at that measurement she was measuring at about 28 weeks so they were kind of worried for her so because they didn't have the necessary equipment I ended up getting shipped to North Bay where the doctors were amazing and so helpful but, that day is just-everything overwhelming. Overwhelming because I kept getting news, I was alone at that point and of course my partner knew right away so he was coming with his mum and my family too was on route to follow behind me. After they took us into the hospital I got set up and everything and got ready to go and have Lily and when Lily was born they had to take her right away because she was having her own complications. She has some heart issues, and she was having blood sugar issues and stuff like that so she needed a lot of assistance so, they ended up taking her right away. So, once I was healed up and back in my room the doctors were finally able to come in and talk with me um, they had asked-because I had seen her briefly, maybe a minute or two before they had whisked her away so they had really a lot of concerns about her health so they had asked 'You know, did you notice anything different about Lily? Did you notice some things might- her facial features might look different?' or they started pointing out a whole bunch of things and I'm like no, no cause I'm like I didn't even get to inspect her, I didn't get to look at her, I didn't get to really do any of that um, as a mum usually does. I know when I had my son they plopped him right on top me and you know, that was good but I was really grateful for the doctors and everybody to you know, do their jobs [laughs] and be on top of that um, so after about 6 hours of Lily being born and at the hospital um, they had a lot of extreme health issues with her like I said so they weren't comfortable keeping Lily in North Bay with me so they made some calls and they got her a place at the- at CHEO, which is the Children's Hospital of Eastern Ontario, which is located in Ottawa. So, they airplane came, and they picked her up and whisked her away. Um, so unfortunately for me just because I had major surgery myself, they wouldn't let me leave so the next day and the day after I worked really hard to get out of bed everyday and focus on walking and just going to see her. I wanted to be released as soon as I could so that I could go be with her. So, that was a very uh, honestly that was a very traumatizing day for me uh, and still at times it can be [voice wavers] it's overwhelming, it's um, it's triggering and it's really hard sometimes when it comes around her birthday because I want to celebrate her and her life and all of her accomplishments and at times that can be difficult for me but we all have to push forward and work towards everyday just you know, be grateful for what-the time that we do have -[internet froze]- that she has accomplished and everything. So, our life consists of a lot of doctor's appointments and hospitals um, they have since Lily has been born as I've just been saying [laughs]. So, when Lily was born, she was at the hospital- we were there for two months um, it's coming up her anniversary of when she'd come home on December the 2nd is the day that we were-that she was released to come home. Happiest day ever but yeah, our life is a lot of doctor's appointments. Like I said, Lily has many health issues um, one of them being aspiration pneumonia and chronic pneumonia. So, sometimes she- we get hospitalized for that so, there's a lot of bloodwork involved, a lot of x-rays involved, a lot of people involved and because I live in the Quebec border, Lily's main care provider is here on the Quebec side and she

is an amazing doctor but being in Quebec it usually is a language barrier [laughs] for me um, I do not speak French. I understand very little. I've worked mainly in the food industry here in Quebec, so I know food, I've got that covered but that's about it [laughs]. I usually travel to Ontario just because where I'm located it's for me I'm on the Quebec side it's like 30 kilometres to the hospital and then if I travel to Ontario it's like 25 kilometres so it is technically closer and they speak English [laughs] which, is a bonus for us so it just- it ends up being a lot [internet froze] travel to Ontario so it mainly does get there but sometimes if our local hospital is not really equipped we do end up travelling quite a bit. Lily has had three surgeries before. Her first one was at four months old, which was her cardiac surgery to repair [internet froze] heart, that went off great, quick, fast- well it was a long procedure, I lied but her healing time did so well um, after we were only in hospital I think a week and a half two weeks and then we were able to go home after that and everything went so well, so good. Her heart is still doing really well and good. There has been a few concerns since then but we'll adjust those when need be. But like I said once again we travel once a year to see her cardiologist and at times when there's issues [internet froze] she heals very fast I think 15, 20 minute surgeries also, she attends CHEO to do those. CHEO is still a very big part of our lives, we go there often that's where all of our specialists are so I'm grateful for that to have a place where I don't have to repeat everything every time I go to the hospital because that's hard, especially if they don't know you. I have to repeat my whole daughter's life history and there's so much medical history in that file it becomes difficult to remember dates, times, that type of thing so it's a lot of being organized on my part having things written down and organized and stuff ahead of time. Um, but her tubes is doing very well, hearing is doing very well she does still have a few issues but nothing of big concern right now so grateful for that and uh, let's see. We have regular appointments also. We see her occupational therapist; she sees her a few times a week. We see a speech therapist every week uh, we see respirologists, we see cardiologists, we see ENTs, we see pediatricians [laughs], we see ophthalmology, there's endless appointments in our lives I could go on forever about the amount of appointments we have so I'm not going to [laughs]. I'm going to continue on. So, here in our community I get a lot of our services here at the health centre. I am so grateful for the services that our local community has because a lot of Indigenous communities in Canada do not have services that are offered to their community. So, our health and wellness centre has- since I've moved around here- they have grown, they've expanded and stuff like that so, I'm really grateful for that because back before a lot of these services didn't exist here either. We receive most of our services there and they include nurses, doctors, dental hygenists, they offer medical transportation to and from appointments. We also have Jordan's Principle- amazing, amazing program, I use it often [laughs]. They also have mom support groups, which is important for my own opinion, for my self care, for my needs, for me to be able to be strong enough to take care of all of my family's needs on top of that. Then we have- like I said my son has autism spectrum disorder, so they have youth services and stuff that he's able to access just because he has some social needs that he really struggles with um, so, it's really

nice that they have different- for instance they have a cooking program so my son signed up for that. So, once every two weeks he goes and he's with peers and he's able to practice life skills and he's also able to have open communication with other people and just also feel part of his community. Because I think it's important- I think sometimes a lot of people with special needs are not really known or don't really feel a part of their community so I feel that's really important. I'm a very active member in my community and I try to attend as much events, help, and participate in any way that I can and I try to teach my children to do that also. So, that's why we also attend our health centre they have so many events and so many family oriented stuff too and it's really great so it's nice to get out as a family and also it's nice to- I spread a lot of awareness about Autism and about Down Syndrome in my community because I feel that it's important for people to understand a little bit about Autism and a little bit about Down Syndrome you know that they are people just like everybody else who have feelings and emotions and want to be loved and want to be respected and want to be you know, feel a part of just like everyone else. So, we are so grateful for them. They also have Brighter Futures there's a lot of programs we use from when our children were a lot smaller than they are now, they're getting kind of older so they're fitting in different categories here and then Lily's occupational therapy services also are at the health centre, So, for instance when Lily was born there was no- like the health centre didn't really have any occupational services they always reached out somewhere else and tried to find or bring people back into the community to help. Um, but the need has increased since then not only for my children but for other people's children in the community also so, I'm so grateful that Jordan's Principle was able to help and they were able to get an occupational therapist and she in turn agreed to stay here in the community and work here out of the community. So, it's really helpful and beneficial to all of the kids here in the community so, we're so grateful for that. Then next I want to talk about my favourite, Jordan's Principle [laughs]. So, like I said I use their services very often. This program is for all Indigenous children across Canada. This program allows parents, doctors, therapists, teachers, et cetera to access funds to aid in the growth and development of Indigenous children which, I feel is so important. There's a lot of services that are out there but even for non-Indigenous communities if you look for an occupational therapist or a speech and language pathologist the waitlists are endless, endless, endless waitlists and then you do your one block and then you got to wait again before you do another block and then you got to wait again. It can be-it can take a long, long time and for children with special needs, early intervention is so, so, so, so important. So, having a program like Jordan's Principle allows parents and allows professionals to be able to access that money so that they can see the results a lot quicker [laughs]. So, that they can hire the private people that they can't necessarily afford out of their own budget. A few years ago, my partner and I were only living off of income assistance. It was only last year that he started his job with the construction company here in Temiskaming First Nation so, I know the struggles. I know how it feels to just live you know, welfare cheque to welfare cheque and you know grateful for child tax. At least that comes in the middle for the extras that you need and- but I can't

imagine the cost of glasses and the cost of you know, all this stuff on top of it. That's why I'm so grateful that we have different programs and stuff that we can have to access this so that my children don't have to go without and suffer and they still get the same opportunities as everybody else. So, we've been using Jordan's Principle since about 2016 is kind of when I really found out about it. When- 2015 I think is when the coordinator here started her job. So, that's only when I had found out about it when Lily was born and we were at home [laughs] I received a call and 'here's these services you can access and I'll help and'- so, I'm like great, I could use it! [laughs]. Because we travel so often and all that so it's really beneficial. Lily also gets help from like I said, the occupational therapist and the speech therapist. Here in Quebec, I tried to access those services through provincial Quebec provincial sector, and they had two speaking English people. For the whole area [laughs]. So, and they were full, like their schedules was full and I'm like well I can't have a speech therapist who kind of still sounds not proper English because I'm trying to teach my children English and I want them to be corrected correctly on their English uh, it's important. It just become a long wait, a long wait and time kept getting pushed on and pushed on. Or I would attend appointments and I would not understand anything that they're trying to say so, it becomes pointless to even have this appointment or anything because nothing is really getting done. Yes, you may know what is going on but me, the parent, who is the one with my child all the time doesn't. So, um, that's why I was so grateful that Jordan's Principle was able to help find workers, even if they are from here on the Quebec side that at least speak English properly to help or to even give me proper information when it comes to how to proceed with you know, techniques or how to proceed with different therapy sessions and that type of thing. I need to fully understand how to do that if I want to aid my child in this also, right? So, that's the biggest problem I was encountering with the language anyways here in Quebec. So, Jordan's Principle was able to help with that because [internet froze] I don't speak French, we speak English here in our community, find professionals who also speak English and who are also able to help and you know, who we can all be on the same page. In partnering with Jordan's Principle and having that and asking them for help they were also able to help find a worker who wanted to stay in the community and who wanted to be around and help and who has a full-time job here now. So, this past summer here in our community there was a- well, I guess it was last Spring. There's uh, Algonquin Acres they are a farm, equine therapy um- local equine therapy here in Temiskaming First Nation. One of our community members has started that business of her own. She also has a child with special needs, so she felt the need to start it for other children which, I am so grateful. My daughter Lily loves attending and you know, it helps because we have Jordan's Principle so we're able to go through them to help cover the cost of what it's going to cost for the equine therapy and it also helps cover the cost of um- they have a specialized worker, she comes- she is a friend of the member who owns Algonquin Acres here and she lives in Toronto so she's a behavioural therapist also. So, she comes and here and really breaks down all of the steps and all of the everything, writes an assessment, how they want to proceed, all that type of thing so, we're really, really grateful to have that program here. The kids

love it like all the children here in our community love it, so everybody benefits from it. Uh, let me see here. Also, this past summer we had our first um, day camp just for- specifically for children with special needs. There's quite a few children here in our community who have special needs so they were able- any parent was able to sign up their children. Because our local health centre usually has um, a summer camp program for anybody able to attend but they noticed that a lot of children with special needs were signing up also and they noticed that the people who were in charge of running, they don't really have the training or anything like that so, the speech therapist who comes here she had a break for the summer so she decided that she would uh, offer summer camp. So, she had contacted Jordan's Principle in our local health centre to help coordinate with that and set it all up. So, we were grateful to have that pro- that this year. Lily had a fantastic time, it was open I think four days a week so they did regular kind of summer camp. They went on adventures, they went to the splash pad, and they did crafts, and they did all that fun, good, exciting stuff just like everyone else [laughs]. So, that's what I love! It's different that it's- it's unfortunate I should say that it's not everybody is together um, regardless of your needs or lack of needs so, it would be nice to see in the future but, it's nice that we had that this year. Because before we never had that. It was not an option at all. Everybody had to find a care provider, or respite worker, or the day care if your child was in the range of being at the day care. So, it was really nice to have, and all the kids had such a great time. So, we were so grateful for that. Next slide here. So, other things that I've used Jordan's Principle for um, like I said Lily has Down Syndrome. Here in my community there's only one other individual who has Down Syndrome and she is about my age. Um, so, kind of leaves Lily just you know, not too many peers, not too many you know, people who are like her. Um, I had- I'm in touch with the Canadian Down Syndrome Society of Canada so I am- I signed up- I looked online and I found out that they offer a conference every year. I was able to look up information and I'm like oh my god that would be great it would be so nice to find resources and so nice to you know, meet other people and other families. So, me and my mom we wrote a letter to Jordan's Principle and I'm like the worst they can say is no [laughs]. We explained that we live in a small rural community, and we do not have access to programs and that type of thing that you would find in a city so the Canadian Down Syndrome Society is doing this and I would really love to attend so we did. They approved us and they paid for our hotel stay, they paid for our entrance into the conference, they paid for our gas and mileage to go there and back, they paid for our food, they paid for the whole trip pretty much. So, it was pretty nice, and I was so grateful as a parent to be able to experience going to this conference with my daughter and being with families who are like ours and um, it's unfortunate due to COVID things have stopped with that so, I'm hoping in the near future it's going to restart. Because we had such a fantastic time and I think it's so important whenever any parent has an opportunity to attend a workshop or you know, help better your own knowledge and your own understanding. I think it's so important that you should take that opportunity and reach out to Jordan's Principle, even if you don't have the funds yourself the worst they could say is no and you'll be in the same boat as you are right now [laughs]. So,

take a chance, you never know [laughs]. I've also had to use Jordan's Principle at times too when um, Indian Affairs does not cover so, NIHB is who our coverage is for health needs so, my daughter has needed a prescription for glasses. They only cover a certain amount. I can't even remember what that amount exactly is but I- and I could not afford-like, my daughter's glasses were over \$500 because they had to be a specialized kind because she's a small child and I didn't want them to break after every use [laughs], or step on them or sit on them. So many things can happen with glasses, so they were able to help pay for the difference of what it costs. I was able to get it sent out beforehand so when the glasses came (28:28, inaudible), they were able to send the cheque to the place and I didn't really have to do too much about it. I didn't have to write letters and wait for reimbursements or anything they were able to do it as long as they knew ahead of time which, was great because I knew a lot- months ahead of time before she got her glasses so, it was so great. Um, let me see here (pause, 28:54-29:08). I'm sorry, (pause, 29:10-29:14). I was on such a roll [laughs]. (29:17, inaudible).

Kathryn: Sorry, can you just-

Tamara: So, I-

Kathryn: Sorry, I missed what you just said because the internet froze, so what did you just say?

Tamara: [laughs]. I'm sorry, I drew a blank.

Kathryn: That's okay [laughs].

Tamara: Um-

Kathryn: Is that your last slide or do you have another one?

Tamara: Yes, no that's my last slide.

Kathryn: Okay, I have lots of questions for you-

Tamara: Okay.

Kathryn: I didn't want to interrupt while you were telling-

Tamara: That's alright [laughs].

Kathryn: First, I just wanted to say thank you so much and honestly thank you so much for your beautiful slides and all those pictures of your family, they're absolutely gorgeous.

Tamara: Thank you.

Kathryn: You did such a nice job of telling us about your life and your story and some of the things that are difficult but also a lot of the things that are just really nice about your experience. At the gathering we had a lot of- we had sort of a combination of families, people who experience disability themselves, and then also people who work in early childhood and educational settings. The people who work in those settings wanted to know like, what about families' stories are important for people who are working in services? Is there something from your own experience and now-you've had with both your son and your daughter, you've been doing this work for a while now right [laughs]?

Tamara: Yeah [laughs].

Kathryn: Can you talk to particularly childhood educators but also anybody working in these services that are supportive of young children, what advice would you have for them?

Tamara: Um, advice I'd have for them would be listen to their parents when they speak because sometimes you um- sometimes as parent it feels like we're blown off or we don't know um, because we don't have the job that maybe you have. So, sometimes it is nice for a parent to be asked questions first as opposed to 'this is wrong, they're doing this wrong, or this is a problem,' because I as a parent have heard that many, many of times and I've had doctors and physicians have me relay to them you are not a doctor you are not a- you cannot diagnose a child with something that you're not suited to know. So, at times it would just be nice to as a parent, to feel heard when I speak and to feel that my words have relevance to my child's behaviour or my child's temperament or my child's disability or anything like that. I get brushed off a lot from different professionals. I've been brushed off from occupational therapists, from doctors, from nurses, from other professionals that I've met a long the way. Assuming that I know nothing because I don't have the titles that they have, or I don't have the experience that they have. But they forget that I have the experience with my child, that I have all the experience with my child because I'm there and because I go to the appointments and the sessions and stuff like that so, I think that's really important and I think it's important for you guys to know that too.

Kathryn: Thank you, Tamara. What about having this experience as an Indigenous family- as an Algonquin family? Are there things that are particular about this experience that you think are different for Indigenous families?

Tamara: Uh, I do. I've been- like I said my daughter has been hospitalized on the Quebec side a few times due to her illnesses. The hardest thing on top of the language barrier is they see my daughter's last name is [last name removed] and they know that we are Indigenous people just by that. Um, it's not often you hear that last name, so to be- like, for instance my daughter was at a hospital, and they put the IV in incorrectly

into her arm so the water from the IV was just pooling underneath the skin and it caused her arm to swell up completely. The nurse all she would tell me is 'wow, that's a really cranky baby you have.' I said my daughter is never cranky. My daughter never ever cries she's like the quietest person in the world. She brushed me off. I asked her multiple times to come back into the room to check the IV- they don't care. She just 'it's fine, it's fine, it's fine.' It's only when my mom came in and went kind of crazy on them that things happened, that things changed. My mom's like 'look at her arm! It's swollen you can see the lines of the tape,' and stuff like that so, you know we have to write letters of complaint against the staff there for not listening for not concerning, for not even taking a look especially when four to five hours have passed since that IV was put in her arm. So, you know like to listen is so important and you know, the woman spoke English who I have that day so there was not really a language barrier. It's not like she didn't understand the language that I was speaking. She did understand she just chose not to come in. There's been other times that I've been at other hospitals, and I have administrative assistants coming into my daughter's room and almost arguing with me about who my healthcare- insurance care provider is and when I tell them you know it's NIHB they look lost as to they don't know what that is that they've never heard of that in their life. And I'm like well if I know what it is this is your job you should know what this is you know, so small arguments like that to the point where I was yelling, and the nurse actually had to come tell us both to leave my daughter's room because of it you know what I mean? So, I'm here with my sick kid, I'm not really here to sit here and argue with you and if you can't find the words to talk to a person then maybe you shouldn't be in this career path. That's just my personal opinion um, but I've had many a times where- another there was an issue about coverage or about stays or I've been told by people 'it takes too long for the money to come.' I'm like well I don't control the money. Phone the government like they're the ones who control the money, I don't control it, and this is who I get my funding from so I shouldn't be looked at poorly or being given less service or my children shouldn't be given less service because of anything. Like I've even had questions 'why are you in Ontario if you're from Quebec?' You know, and I have to sit there and justify why I'm here. I don't speak the same language as they do I don't- they're not helpful in any way with me you know, and I shouldn't have to justify that. I live in Canada [laughs] just like everyone else does regardless of what province I'm in you know. My NIHB service is covered by the government and can be accessed in any province I choose to go to for medical care. It doesn't matter why I'm in this province or what brought me to this province or anything like that and I think people forget that. Sometimes as professional people there's a lot of circumstances happening and you- you're, you don't know this person, you don't know their life, you don't know nothing. So, to you know, have a little respect can go a long and to have a little bit of you know, common respect and decency would also go a long way between relationships, between Indigenous people and non-Indigenous people in our country.

Kathryn: Thank you for that.

Tamara: Thank you [laughs].

Kathryn: And you know I- when I um, we've met before, and I've often thought in hearing your story about the- how much your story illustrates the way these colonial borders have been placed upon Indigenous nations.

Tamara: Yes.

Kathryn: So, Quebec and Ontario are colonial, political areas. They're not Indigenous-

Tamara: No.

Kathryn: (38:23, inaudible) but that is being imposed on your-on you.

Tamara: Yeah.

Kathryn: Um, I'm interested in uh, you talked about going to this conference about Down Syndrome and meeting other children who have Down Syndrome and one thing that comes up for us in our research we're interested in is intersectional identity. So, what does it mean to have disability as a part of who you are and that human difference as being a valued part of who you are, and also holding an identity as an Indigenous person. So, I'm interested here and correct me if I'm putting my words on to your story, but you know, you left your community to find other children- other families who had that experience but you also within your community have described finding important social relationships and connections. So, I'm wondering if you can talk a little bit about that intersectional identity. What does it mean to have a child with Down Syndrome and to be both Indigenous and part of that disability community?

Tamara: Um, okay. Um [pause, laughs], honestly, when I attended that conference, I felt very intimidated when I walked in because I didn't know what to expect. Because I've never met more than one person with Down Syndrome at a time. Um, because of you know a lot of things but the welcomingness that I felt from you know, the people who were there I can't- I can't describe that. I've never met anybody, like any person at that conference. I knew my mom and Lily and that was the only people I knew- my sister, my sister ended up coming with us. Um, but I didn't know anybody I didn't know what to expect and I myself have anxiety and I myself have you know, a harder time to just go out there and introduce myself and Lily did it. Lily brought everyone to us. Everybody wanted to see her. She's beautiful, she's you know, so sweet. Everybody had to come and see her, and they loved her pigtails and they you know, loved who she was and she drew everyone in. That made me feel so relieved because I'm like how am I going to- how do I start a conversation? How do I you know, just walk up to somebody and you know, strike up a conversation? I didn't know and that day of I was so feeling very overwhelmed and very excited to be there but, very overwhelmed at the same time. So, being you know, having that community and now having met friends there and having met other people you know, and having people I can reach out to now as a parent to

other parents who know what it's like um, I'm so grateful for that. I cannot describe how much that means like, even now here living where I am I have a few friends who are located in New Liskeard whose children also have Down Syndrome. Their children are not necessarily in the same age bracket as my daughter, theirs is older but I kind of like that because I'm like 'okay what did you do when this happened?' or 'what was your experience like?' or you know, appointments, medical stuff just have somebody to listen and you know hear my frustration when I need to talk about you know being overwhelmed about surgeries or being you know tired from lack of sleep because we were up all night because Lily has sleep apnea. You know what I mean? So, to have other parents who are able to relate that is so important and it wasn't even- because a lot of those people were not Indigenous people. They were people from all different races, so you know, it was really nice to see just people coming together and having someone in their life who is connected to a group bigger than themselves. Lily hugged so many people and they felt so much love for each other. I can't describe it. When you meet a person with Down Syndrome they're so loving. I can't describe it any other way. I met so many young adults and so many older adults at the conference you know. It was so nice to see. To ask them, to talk to them about their lives, to talk to them about things they felt in their life that was challenging and overwhelming, and in their opinion, what they wish others could do or how things could have been different. Or how people can change and stuff like that so I found that was so important to be able to have that opportunity to meet them because if I wouldn't have attended this conference, I probably wouldn't know a lot of the people that I know now. I wouldn't have the friendships with people that I have now. Even small things like Facebook. There's so many groups on Facebook you just type it in you'd be surprised so, it's so nice like I have so many people I reach out on there to you know, I can ask my questions and not feel judged in any way. To have an open conversation with like-minded families you know, that's so important. Because here at home it's lonely. It's hard at home. Sure, I can talk about my kids until I'm blue in the face and I can talk with endless parents here but nobody's going to fully understand where I'm coming from when it comes to Lily because Lily's the only person here who is like she is. Like I said, there's one other person but she's about my age so it's not like they can hang out and play and have a discussion because you know, they're too- their age gap is totally different from each other. So, it makes it harder and at times I also feel that for Lily. Is she going to feel unwanted or unaccepted in her community because she's the only person like she is? Is she going to feel overwhelmed or stressed or you know? As a parent I wanted to know what I could do so at that conference I was able to ask everyone my questions and get honest answers and responses back you know? Not feel judged because I'm asking such random questions at times because at times, I was like I don't know. I had no idea and learning how to speak about people with Down Syndrome. That they are a person first and not a diagnosis first and at times people forget that. At times I forget that. At times my family forgets that, and you know, it's so important like that's why I'm so grateful that I was able to attend these places because here at home like I try to spread so much awareness and try to correct people when they are being incorrect or when

they have false information that's you know, not relevant anymore or you know, old ideologies from before on how people used to think um, you know that type of thing? So, I feel that being out and being able to connect with other families was so important and especially for me. I'm from a small Indigenous community where we don't really have access to that type of thing so, I can't even go to say like uh, what do you say like a community office where you can kind of you know, find out about diagnosis or find out about different specialised programs that type of thing like I don't really have that as an option here. I have to start that. You know, my community has to start that and stuff like that, so I always try to bring back any knowledge or any experiences that I hear of anywhere else so that my community does have that too so that we're more able to, um, better help my daughter down the road feel a part of. Feel that she is accepted in her community regardless of who she is or what label she attached to her or what diagnoses she has attached to her so those, like I said, that conference changed my life [laughs]. That conference changed my life.

Kathryn: Well, thank you so much Tamara. I think we're out of time but, I appreciate you sharing your story so much and thinking about it from different aspects of Lily's identity but also hearing about the work that you have done too for your community, for your daughter and for yourself. I think it's just tremendously important for us to hear that story so thank you so much for your time today.

Tamara: Thank you. Thank you, Kathryn [laughs].

Kathryn: [laughs].

End: 48:29