

## StreamBox

City of Waterloo/Kitchener

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>> Ryan: All right every is set here. So it is Ryan from CNIB just waiting about eight minutes until we get started, for those out in the gallery you might see some videos being turned off or on or hear some silence, but if you can hear my voice you are connected correctly.

>> It's Ryan from CNIB, welcome to those who just joined us, I noticed a couple more people. So we're just hanging on here for about five minutes or so, but if you can hear my voice you are connected properly, you might hear some videos going off and on but everything is good as long as you can hear my voice.

>> It's Ryan from CNIB. We got four minutes before we begin.

>> It's ripe from CNIB, welcome to those new people out there in the gallery. We're just waiting a couple more minutes, 57 past the hour, we have about three minutes before we begin.

>> All right panelists, we got one minute. Final check, we're going to start in about a minute or so once you hear the verbal recording we will be all set to go. (recording: This meeting is being recorded)

>> Marina Dotzert: Hello and welcome do day four of our five day Webinar series called Life Made Accessible, in honour of National AccessAbility Week which takes place from May 31 to June 6, National AccessAbility Week is a time when accessibility and inclusion are promoted across communities and workplaces. And a time to celebrate the contributions of Canadians with disabilities. It is an opportunity to recognise the efforts of Canadian whose are actively removing barriers and ensuring persons with disabilities have an equal chance to participate in all aspects of Canadian society. My name is Marina Dotzert, I work for City of Kitchener as inclusion services coordinator and today I'm your host. Our event Life Made Accessible is an opportunity to see into the lives being presented to you, by listening, asking and learning we hope we will give you better understanding of the paths some individuals with disabilities need to take. With understanding we hope it will lead to a world more accessible. For today's Webinar, we will look at disability within the family. But before we begin, Spirit of this event is an opportunity to listen, ask and learn. Our panelists will be sharing personal experiences and perspectives, this is their story. They do not speak on behalf of all individuals living with a disability. We encourage you to comment and ask questions to our panelists throughout the Webinar. Using the Q and A option at the bottom of your screen. The last 10 to 15 minutes of our time together will be dedicated, sorry, dedicated to anticipating your questions. Please remember to be appropriate and courteous. Video remote interpreting is available for this

event, please change your view to gallery view to see them, captioning is also available which you can select at the bottom of your screen. A very big thank you to the City of Kitchener and City of Waterloo for sponsoring our interpreters, captioning and transcription services for today. If you are using a computer with a screen reader, you can navigate your Webinar options using the tab key. If you are joining us from an iPhone app using voiceover your Webinar options are located at the bottom of your screen. To activate the buttons use a single finger double tap. To begin I would like to introduce our moderator for today, Edward Fars. Edward has been an advocate for people with disabilities for many years hosting seminars about human rights across southern Ontario. He is also representative of Canada as starting goalie at the first ever power wheelchair Hockey world championship in Holland. His Jersey hangs proudly in the Hockey Hall of Fame. KW Accessibility, a non-profit agency that serves adults with disabilities. Over to you Edward.

>> Edward Faruzel: Great, thank you very much Marina. So today we're going to be talking about families and people with disabilities in families, but it is going to be a little bit of a unique look at the family dynamic. Each family member experiences disabilities through their own unique lenses, in this session our panelists will discuss their family dynamic and how they manage complex challenges that other families may not have to address. To begin I would like to introduce our guests. First of all, Dan Lajole, Dan is a lifelong advocate for accessibility and inclusion in our community. Lived experience serves as a launching point to his professional pursuits where he has spent decades working in communities supports for people with disabilities. Including his current role as Community Resource Coordinator for the independent living centre of Waterloo Region. Dan is also a private accessibility consultant specializing in Corporate website and document accessibility. On top of all of that Dan is a proud father of two amazing kids. Welcome Dan.

>> Dan Lajole: Thanks for having me Ed.

>> Edward Faruzel: Amanda Hearn, hello Amanda. Amanda is a single mom of an energetic ten year old, who keeps her very busy. Amanda is extremely passionate about the topic of family and disability. Having her son was one of her biggest fears, but now he is her biggest blessing. Amanda is currently a student at [Name?] college studying remotely from home due to COVID-19. Netflix, puzzles and the joy of extra time with her son has become their survival tool during this isolation period. Welcome Amanda.

>> Amanda Hearn: Thanks for having me Ed.

>> Edward Faruzel: Elio Riggillo, Elio has been married for almost 25 years to his wife Tracy and they have three children. He works four jobs as a grocery clerk at two different stores and then instructor for the GBC Intervenor program. And as community relations coordinator at the Canadian Helen Keller centre. Elio was born and raised in Toronto, he has [Name?] syndrome and is profoundly Deaf with gradual vision loss. Elio uses American Sign Language to communicate, but as his vision has deteriorated he now uses tactile ASL to communicate. He is also started using protactile communication in addition to American Sign Language. Hello Elio, welcome and thank you for joining us today.

>> Elio Riggillo: Hello. Very happy to be here.

>> Edward Faruzel: Great, thank you. All right. Well let's dive right into this topic. Can you guys expand a little bit upon your stories, I read your introduction, but perhaps you could just expand

a little bit on the details for us. Dan do you want to start us off?

>> Dan Lajole: Not now with the mic unmuted, absolutely. I do want to apologize in advance, there is a great deal of construction happening outside of my building right now, so if you hear a lot of beeping you can tell that they are back from lunch and the machines are going. So my apologies if that's a disruption. You know, I was really excited to speak on the panel today, you know I, in my world I have the opportunity to speak on many issues surrounding accessibility but um not ever have I ever been able to speak about being a parent. It is pretty unique. I have to say though as this panel got closer I started to get nervous about what I was going to say about being a parent with a disability. It's hard to differentiate between what would be a unique experience for me versus what would just be a typical parenting story which many of us have. You know, I can look back and say that I've always wanted to have kids, you know my mom tells a story that when I was a kid I always said that when I grow up I want to be married, I want to have kids and I want to be rich. Well I got two of those three so far, but it's always been um a part of what I wanted and I knew that there would be challenges. I mean maybe when I was younger I didn't really think of it, but as I got older of course I appreciated that having a disability would, would mean that things were going to be a little bit different for me to raise children. Luckily for me I met a great partner, my wife Maggie who um, you know, what can I say obviously, you know, I'm sure when we met and we got married we spoke a lot about having children and I'm sure she had some of her friends maybe and family saying, are you sure about this? But she was, you know, willing and it was always a part of our plan so certainly without her support it would be a different story for me for sure. But you know we move forward and we had our youngest, he is a, sorry our oldest now, he is a teenager. So friendly parents out there of teenagers, you know what that means. You know, it was really interested when we first, when Maggie was first pregnant. Our doctor, who was my family doctor at the time asked her if she was going to get an abortion because my disability is genetic, so he just sort of said oh I'm assuming then you'll want to plan for an abortion, she couldn't believe her ears. I went with her on her next appointment and sure enough he said it again, this time with me in the room. So needless to say we changed doctors after that meeting. But I think it goes to show, even then, you know, what some of the perceptions around disability are, you know obviously this doctor, you know, sort of thinking um either A, will the child be disabled and/or B, how will they cope seeing how one parent has a disability, you know. But I mean that's a bit of a dark sort of story, but I mean since then I'm, it's been amazing. I mean like most parents um my children are, you know, the most important part of my life, I don't tell them that of course because what kind of parent would I be if I told them that every day, they have to see me as a bad guy from time to time or I'm not doing my job, so you know they are amazing kids and I mean they've grown up in a world where they don't know anything other than having a dad who is a wheelchair user. You know, I doubt they would be able to distinguish what that meant, you know, I'm dad. Right sometimes I'm the good guy, sometimes I'm the bad guy, you know my son, I was just joking earlier today.

My son basically grew up sitting on my foot rest, he loves sitting on my foot rest, wherever he would go he would always be on my foot rest just sitting, cause you know he was a little kid and didn't want to walk. So I would take him everywhere sitting there and I remember this story, he had to get some, we had to go to mechanical mass McMasser hospital, you can imagine a

toddler sitting on my foot rest, enter the hospital, up until that very moment he had never fallen off my wheelchair ever, of course he chose to, in the middle of the lobby of McMaster hospital with all these doctors and nurses and professionals watching, decide to, you know, flop face first off my chair in front of me. I had to like jam on the breaks, thank God I didn't run him over, that would be of been interesting in the hospital. But you know that anecdote for me is sort of indicative of the way we just sort of interact with each other. I mean my, being a wheelchair to them I don't think is really impacted them negatively. I often look at the benefits of what my disability have brought into our family um and into the children's up bringing, you know I think the fact they yet to be a part of a unique world and to understand and see difference in people from an early age as hopefully been a benefit it them. I'm sure again it won't be something they really realize until they are older and they can look back but um yeah it's been great. We will talk more as the session goes on, I just want to say I do, oh my God I can't believe I forgot my daughter. I have two children. And they are both amazing. Their pith days are in July, both of them and yes it was planned that way. We wanted to have them same time so my son is turning 16 and my daughter Mia is turning 11 in July. Don't ask me what their birthdays are because my son is convinced I don't remember what his birthday is so, but yeah.

>> Edward Faruzel: That's great Dan, I'm very happy that you didn't run over your child.

[LAUGHTER]

>> Dan Lajole: I've run over them other times, but that was the first public running over.

>> Edward Faruzel: Ahh, that was probably intentional. [LAUGHTER] All right. Amanda, moving on. Why don't you tell us a little bit about your story.

>> Amanda Hearn: Um my story actually started as a surprise. My son was a birthday present I wasn't expecting, I was young and um due to my disability and different things I actually didn't find out that I was going to have a baby until I was seven months pregnant so, that in itself was horrifying. But it was a situation I handled, I did get asked by a few family members and a few friends if approximate I was going to consider adoption because I was single and young and how do I care for a baby when I have a disability. Luckily for me, I have an amazing family and a grandmother who is beyond no other, who offered to move in with me and Owin and we lived in a three bedroom apartment so everything was on one level. As the years go on, to say that it wasn't difficult is an understatement for Owen I feel like Dan said, opening his eyes to a completely different world than his peers has, you know, allowed him to grow with much more compassion towards others and he is very helpful, which is good now that he is older. And that's where that fear of being 19, single and pregnant was horrifying, but now as him and I have grown together it is the greatest gift in my world and he reminds me every day that we're all normal, just everyone is different in their own way. So it is definitely regarding and like Dan I have had some pretty funny instances, one where Owen likes to push me in my wheelchair because I'm in a manual chair and we were actually going down the street one day and he hit a bump and luckily for me I have the reflexes to put my feet out if my chair goes forward. I've never seen the kid so scared in his life because he thought he was going to flip me out of my chair forward. So I'm sure as Dan can attest, we can come up with many stories where that can put the fear of God in our kids faster than any punishment. [LAUGHTER] But other than that, it's been a joyous ride and I'm sure we will get into more as the Webinar continues.

>> Edward Faruzel: That's great, yeah thank you for sharing that with us. I'm sure it would of

been quite a shock for him to see his mother go flying. All right Elio would you, could you tell us a little bit about your situation?

>> Elio Riggillo: Yes, thank you. Hello everyone. I hope you can see me clearly and you can see me signing, this is a good background. (clearing throat) My experience as the other individuals have said, I grew up as being Deaf I didn't know that I would be DeafBlind, I went for to a school for the Deaf and I was using American Sign Language and I noted that I was starting to misunderstand or miss what people were signing at the age of 16 and that's when I found out that I was DeafBlind and it was a challenge for me to understand what that would entail as time went on. And then when I was 30 years old I became an advocate within the DeafBlind community and started working for the Canadian Helen Keller Centre and working one-on-one with individuals educating them with family members on various different issues and topics. And educating the Deaf community as well and the DeafBlind community. I graduated from High School and then at that time I started working at a grocery store and I have done so for some time and then I attended, I was planning on attending Gallaudet University, so that was what I was thinking about doing but then I ended updating my wife Tracy and then we got married and then I had a decision to make as to whether I was going to go to Gallaudet University or get married and start a family and so I put my dream or my goal of going to Gallaudet University aside and I started working so that I could support my family. At that time I could use interpreting services and I was able to see American Sign Language, but I did see and so then that I continued to meet other individuals who were DeafBlind and I was learning more information from them and then also I had, with my wife Tracy, we had three children. So I have a son that's 23, a daughter that's 21 and a daughter that's 17. All my children are hearing and sighted and I'm the only DeafBlind person in my family. And my family, you know, we've had our challenges around communication, there's, you know, constant changes of how we communicate and I think that's just how things happen within the dynamics and so we just roll with that. So as a DeafBlind father I just see how that's how life works. That's how I see things. When I was 30 years old I started using intervening services and lobbying and advocating to the government for intervention services for DeafBlind individuals the number of hours would increase during the week of provision of intervention services. As a father it is my responsibility and my wife for our family so that I would be able to work and support our family just like everybody else. It supports their family, I had that opportunity. Now what's happening we have COVID-19 and since the pandemic started I've been able to work at home in my home office and I use e-mail services and I'm able to attend meetings and then go to work on the weekends and I have PPE that is provided for me. So I'm able to have those supports when I need them. I am able to walk and I use a white cane there have been times when I have fallen or tripped over things or bumped into things so then I decided to use a white cane because it wasn't, it wasn't comfortable for me to have people looking at me seeing me bump into things, that kind of thing. And so it also using the white cane of, after I received training I became more comfortable with it so it allowed me to avoid bumping into people and obstacles and that kind of thing. It was much better once I received training and I was able to use a white cane. Some people still do not recognise the white cane or what that means, many people on their phones texting and not paying attention, so we still have some collisions with people who are not paying attention and also there has been some close calls as well as with vehicles, sometimes able to, at the last

minute the driver of the vehicle will see me and avoid hitting me. Another thing that happens is people people wanting to rely on my children or rely on my wife I do sometimes have to do that if there is not an availability for services then I do have to rely on my wife for supports as a backup. As I said I had four jobs, very, very busy and I can do many things I think DeafBlind people can do things, what it means to be DeafBlind is that as my vision progresses it does mean I have to change how I do some things and it is how I have changed my communication. So I use tactile ASL and protactile ASL, I don't hear and I can't see. When that happens then I will be able to use protactile communication. That's basically it. Thank you.

>> Edward Faruzel: That's great, thank you very much for sharing that with us. One of the things that each one of you mentioned was different service, supports that you do get in the community, how is that changed because of your children? I know Dan you get some care service, are there any other resources that help with, with you with looking after your children?

>> Dan Lajole: Yes, I mean I think everyone would have access to different sort of resources, you know, for me receiving care receiving people in our home to help me with stuff has been sort of one of those issues that I guess would be different than a typical situation and something that our kids have grown up used to and Maggie and I are pretty purposeful when it comes to setting that environment so that it it's natural but at the same time doesn't they still feel like it is their home. So it is sort of that gray area of these people are here to help dad, you know, don't pay them no attention, but at the same time these are human beings helping dad, so you know, they become part of our extended sort of household in many ways. So that's something that, you know, we do deal with all the time and very fortunate to have that type of support. I know that some agencies provide, can provide additional support for parents who need some help with the kids.

Yeah I mean that's definitely one of the resources that's out there. I mean it's, you know, I'm not sure if you want to present a list of different types of things out there or if you want to hear from other people about maybe how they have incorporated their sort of support services into their daily existence.

>> Edward Faruzel: Well no, I think that's great. I'm sure the resources will, are out there for somebody needs them they could probably contact you at the independent living centre to get a list of those.

>> Dan Lajole: Yeah so I mean for those of you who know me, I mean my job human resource coordinator is to help people find information, resources and to connect with either agencies or each other in the community. So certainly if anybody needed information um you can contact myself through the independent living centre or any of the other host agencies that are putting on this Webinar series. Each of us have sort of a lot of different resources that we can provide. So that would be a great place to start and you can get a list of those on the City of Kitchener website where people registered for this event.

>> Edward Faruzel: Perfect, thank you. How about Amanda? You had your family, you said your family was helping you out quite a bit. Are there other resources that you've been able to utilize to help with the parenting process?

>> Amanda Hearn: My family has been my biggest support system, as once I had Owin I actually met Dan at the independent living centre and we were working on different resources to kind of bring to the community for parents with disabilities, I myself don't need attendant

care so one of my biggest things that has helped me within the region is [audio cut out] the Independent Living Centre. I have always met a lot of people with accessibility which I belong to. So it um, that's where I've gotten a lot of my resources within the community just getting out there and meeting new people.

>> Edward Faruzel: Yeah I think that's really important for all families is to have that social interaction with other people also, right. In the community and friends, family are great, but friends, friends are awesome too. So that's wonderful. Elio, are there any resources that you could tell us about in Toronto that have helped you along the way. Maybe in being a parent of with a disability.

>> Okay. Here we have intervening services and so for example when I go grocery shopping or to a doctors appointment the family yeah then I can go out and go grocery shopping and bring that back home. Sometimes my son will be busy, the kids will be busy doing stuff. So we share a lot of responsibilities around the home. And then when I go to the doctor with the kids before when I didn't have an interpreter we have to write everything back and forth but now I can have the Intervenor come with me to the doctors appointments to meet with them. The only thing is Intervenor can't drive my children there so there is that responsibility yet. And so we meet there, we have the meeting, then we go our separate ways. But I can't drive being DeafBlind, so that's not safe. Because the white cane is not going to help me drive the car at all so -- true story though, I did want to get my driver license, I remember this was like 35 years ago, now you got the G1, the G2, the graduated licensing, much different than it was before. So I did pass the first, because I failed the first time and like oh why did I fail my drivers test, I think it was the vision test, that seemed to go okay. The written test was all right. But then they said that I had failed and I guess because the lights and peripheral vision, that's where they caught me. So the second time I went I passed because I didn't keep my eyes straight ahead, I kept looking to the sides because I was very excited so I did actually pass and then High School teacher came and said I heard you got your license, I said yes, he said you can't drive because of your vision problem. He said in the future your vision is just going to get worse. And so for me there is a grieving process of that, I know all my frindz were getting their driver licenses and I wasn't able to. There is that competition among the teens on who is going to get their driver license first, unfortunately I couldn't go through it. But how to accept it. So my teacher had told my father no I shouldn't be allowed to drive. Decide to book the eye test at that time, that's when they were doing the drops and looked and that's when they found out I did have Usher syndrome. Type one. So went on from there.

>> Edward Faruzel: Thank you very much. That would of been very interesting if you had gotten your drivers license. All right let's, let's move on to something fun. How do you think your kids would describe you as a parent? If we ask them right now, what would they say about you? Let's start it off with Dan.

>> Dan Lajole: Every parent knows better than to ask their kid what they think of them right now. You know it is funny, I actually did because we talked about it with them this morning I said so what do you guys think of me right now and I'll give you my sons quote, he was being funny, he was like sometimes legit, sometimes not so legit. That was my son's answer. Yeah, you know, I always joke I'm still waiting, haven't got for me yet, I'm still waiting want my coffee mug that says meanest dad ever. I think cause, you know, if you are being a mean parent chances are

you are being a good parent in my, my with that said, you know, I think I have a pretty good relationship with both my kids. We communicate a lot because I don't have that sort of physical interaction with them, you know, play catch or whatever, pick him up, swim around, whatever. So a lot of our interactions obviously are verbal and whether it's through regular communication, music, stories, I mean whatever the case may be a lot of it has been verbal and I think the benefit of that has been, we have, we have a relationship that's really pretty familiar, you know. They know who I am, I know who they are, I'm really fortunate that, you know, we share a lot of time together that way, so yeah. I hope they say good things about me. I honestly don't know if they will until until they are older, think back to when I was a kid. Hopefully they will think about me fondly, I'm pretty sure they will. If not they are grounded. [LAUGHTER]

>> Edward Faruzel: I haven't heard them say anything bad but yet. So Amanda, how would you what, would Owen say about you?

>> Amanda Hearn: I didn't actually pose the question to him, but I wish I would of now. If you were to ask him he would probably tell you that I'm OCD. He loves to remind me every day that I'm OCD when I'm asking him to pick things up, clean this, do this, and whatever. And he goes mom it's not bad, you are just OCD. So that's his favorite line. That and his new favorite thing is that I'm old. [LAUGHTER] So those would be the two things that you would get from my son if you asked him about me.

>> Edward Faruzel: I know you just did have your COVID birthday.

>> Amanda Hearn: Yes, oh go ahead Dan.

>> Dan Lajole: No you finish, I was just going to add something about being old, it was a joke.

>> Amanda Hearn: I was going to say he loves to remind me I'm hold but anybody older than me is young, ie, Edward.

>> Edward Faruzel: That's --

>> Dan Lajole: So I'll just, being old and your kids perceiving you as being old. So of course my kids call me old all the time and they always say I wear dad shirts, righted. So dad you wear dad shirts and my son loves band shirts so I took one of his band shirts and wore it one day when he was sleeping, so when he woke up I'm wearing his band shirt and actually it fits quite nicely and brand I like, I told him well I'm keeping the shirt. He said that's my shirt, I said yeah you told me you want to wear band shirts, I like this one.

>> Edward Faruzel: That's great. I like the shirt you are wearing today, it looks good. Elio what about your children, how would they describe you?

>> Edward Faruzel: If you ask my kids about me a lot of times they will say how do you communicate with your dad, the kids have to explain that we sign. Because can't hear voice not so much but they have to go through how we communicate, that seems to be the biggest thing, oh DeafBlind, he can be independent so they have to do that explanation. I mean my kids look up to me, you know, they know I love them, you know. Sometimes they call me the moose, that's their nickname for me. Just because I tend to run into things, so they laugh about that. You know, just because when you talk about car accidents and the moose are always getting hit so that's why they nickname me the moose. Yeah they look up to me, I think it has been a positive influence for them, when I talk to them about driving, I can't get it but you guys, they were all very excited to get their driver license, I was excited for them. You know what, go ahead and do it. So try to be very positive with them.

>> Edward Faruzel: That's great, it is wonderful that children can always find some comedy in everything that we do.

>> Dan Lajole: Edk I add a little story about my daughter. I feel like I splengtsed her much and I'm feeling parental guilty, I think all my anecdotes so far have been about my son. I want to say my two kids couldn't be any different. They are just polar opposites in every way and you know, my daughter Mia, she is like so amazingly helpful, you know, with me. You know my son is pretty chill, right, pretty chill. My daughter is like, you know, a lot more sort of um more energy and she has been of my kids she's if I need something done like help with moving something or moving my arm or adjusting my leg or whatever like she is my go to. My son, you know, if I can find him in his dungeon room, is not, is not the most, but my tower is awesome and there is a story I was in the hospital years ago and she was coming to visit and she was like right in there, daddy let me do it, I can do it, I can show you how to do it. So I want to give her props I felt like she wasn't getting any screen time. If she watches this video later I don't want her saying uh dad you didn't talk about me, so there. Now I talked about her.

>> Edward Faruzel: Spoken like a proud father. There is something about dad's and their girls. So we're quickly running out of time. This has been a wonderful session with the three of you. But is there any last minute advice that you would like to give to our viewers today? Any thoughts, just briefly before we start asking questions from the audience. Why don't we start with Amanda, always started with Dan so far. Let's go ladies first this time. Amanda?

>> Amanda Hearn: My advice to anybody if you are starting a family or, you know, if you are having troubles with the family, just be patient everything will happen and just lots of supports among friends and family in the community. Just reach out and ask. You don't know if you don't ask.

>> Edward Faruzel: Great. What about you Elio, are there any last minute thoughts that you would have that you would like to give to our viewers?

>> Edward Faruzel: something within DeafBlind community, you can contact Helen Keller centre, we can talk about resources that are available for people who are DeafBlind, what to do, if there are problems that come up, we can work through that. So I would encourage everyone to contact if issues come up. And if you do have a parent who is DeafBlind, it is the same thing. The children can ask too. So we have resources for everyone. So for people who are DeafBlind also for Deaf. So please contact. We are resources available because I'm the resource coordinator so I can hook you up with anything you need. So it is Elie,@chc, if you need any information you can always e-mail me and let me know. Great.

>> Edward Faruzel: That's terrific. Thank you very much. And what about you Dan, any last minute advice?

>> Dan Lajole: You know, I think that you know when you are going to have children I mean that's the most important relationship you are going to have and you are going to develop that relationship with them regardless of your environment or your situation. I mean families adapt, children adapt. I would say, you know, don't worry about what other people perceive as to whether or not you can or can't or what impact it is going to have. Worry about your kids and raise them in a world where they don't have to feel that, right. A loving family, that's what they shoed feel the most. You know, just support them and love them as any parent would. All the stuff, all the extra stuff, what your needs are, if you use a wheelchair, if you use Sign Language, is

this secondary that's not the issue, your relationship with them will be the thing.

>> That's great advice. Thank you very much. I think looking at the clock I think it's fine to pass things back to Marina and see if we have any questions from our audience.

>> Yeah we do have a couple questions, thank you everyone for participating so far. So obviously parenting is super hard no matter who you are, but what have been some of your biggest fears and greatest moment of being a parent. What have you learned?

>> I can definitely take that one, one of my biggest fears was more so when my son was younger and that I couldn't run around with him and play with him um and what I did learn was that kids are resilient so if you can't chase after them for run after them you find ways to engage still. I would toss a ball in the yard and we would play catch. If the ball goes flying and one of us misses it, my son ran to get it. Don't worry mom, it's okay I got it. It was one of those things to make playing and activity normal. You know I think, for me before my children were born migratest fear they were going to have the same disability as me. Not in a self deputy indicating way, you but I mean just in the sense that I didn't necessarily want them to have to go through what I did, I mean we were prepared if that was going to be the case, that's certainly the fear. When they weren't, this great moment for me when Jacob stood up on his own and for me that was like really good moment because I knew that wasn't going to have to endure the same thing, yeah. So

>> Edward Faruzel: I remember my three children, we went to the park and we were playing and my son had taken off kind of out of my line of vision so I was down to two kids and I became very fearful and so I was, it was disorienting just trying to find him and then I found eventually found him and explained to him when he would go away you have to let me know where you are going, I was very afraid because I was trying, you weren't in my line of vision anymore so and then that was just something that we had to repeat and emphasize over and over again. You do have those moments, those scary moments that happen.

>> Marina Dotzert: Thank you the next question is what was your proudest moment in life, sorry what was your proudest moment in life being a parent with a disability?

>> Amanda Hearn: For me this tends to happen on a regular basis when my son and I go out, but one of the proudest moments for me to know I have done right by raising my son is when we go out, if he is pushing me in my wheelchair or if I'm walking and I need a hand, he will be the first one, here mom take my shoulder or let me push your chair. I have had people stop me and commend my son for being a great young man. So that's, to me, one of my proudest moments.

>> Dan Lajole: In a similar fashion, you know I think I'm just proud of I mean sounds so clich'e a lot of pearntsz are the same I mean I'm just proud of those kids, you know, I think that they are, you know, we are lucky they are both very well spoken and they are sort of, you know, in their own way um pretty good people to hang out with. So just proud of that, proud that Maggie and I have been a part of that and proud to see that, you know, the way we have raised them and the way we have incorporated our life into their life um has been a benefit and made them into some pretty cool young people.

>> Edward Faruzel: I'm proud of my children, I'm very proud of school accomplishments they have made. My son is going to be graduating from college, I'm very proud of him. I have daughter in University and one to graduate from High School soon and they have, my

daughters, my daughter received the history award and I was very proud of her for that accomplishment in school. Sorry. She was a valedictorian, gave the valedictorian speech. Both of them did that. So and that was a great honour. I was very proud of them in that, at that time. Now just been very impressed like how much they have worked diligently at school and enjoyed school and all that they have accomplished through University and college. And High School.

>> Marina Dotzert: Probably have time for one more question. So what has been the most difficult part of being a parent with a disability? And maybe some of you can touch on somebody might have commercial support workers, extra doctor appointments you have to attend, sometimes maybe medical complications, physio may have all been part of your life. How do you think this is perceived by our kids and how do you approach that conversation when times could seem a little scary or nerve wracking.

>> Dan Lajole: Yeah I mean for sure it is not something, you never want your kids to see you in a position of vulnerability or weakness necessarily, I mean happens but you are welcome to sort of see as a parent, especially when you are really young. I know that for me when I was in hospital for an extended period a couple years ago, you know and my wife was there a lot helping, you know, my kids were staying with my parents, that was really hard for, for me. I'm not sure if it was [Name?] for them or not. Stay with grandma and grandpa for that time but you know that I think that was really hard, you know, knowing they just wanted to have their lives back and that it was because of me they were sort of, you know, in turmoil I would say that was definitely a difficult part. But with that said, you know that's life, right. Everybody has unique situations and everybody has different burdens and I think that, you know, for our family that's just something they have grown up with, that dad sometimes requires more help, sometimes dad, you know, can't participate in the same way or sometimes, you know, dad has another doctors appointment, you know, but it is sort of their world. I mean they don't know any different. If we don't draw it out, don't draw attention to it. Almost like shows shoes, going to work, just part of our day. We sort of, that's our world.

>> Amanda Hearn: I would concur with what Dan said. I would say one of my hardest things as a parent is days where I'm really sore and I can't do the things like mom should be able to do um, simple things as make dinner, so with my son being ten, craft dinner or frozen pizza I'm lucky he is very helpful that way, he knows when he is a bad day difficult to think that my ten year old is cooking dinner because I'm kind of stuck on the couch. So that's a hard pill for me to swallow, but at the same time we have a joke in my house where his future wife would thank me down the line.

>> When there is no intervention services that makes things very difficult and challenging and that's something I don't like to rely on family for support too much but I'm, I'm thankful when they do provide that support. If situations like maybe painting needs to be done around the house or something like that, I might ask the kids um or I may have to hire someone like a painter to come in. I would like to be able to paint but sometimes I miss some spots and don't get the paint coverage as I would like it. So there's examples like that. There has been times when, you know, sometimes the cats throwup and you step in it and you don't see it and they are like oh dad, you know. So or just like wait we will clean that up, they are very helpful with things like that, that happen around the house. Kind of life situations happen in every family. My wife is there to be very supportive and now that we're um we're only having intervention

services come once a week because of COVID so, so that I can get out and but I'm have to use like wear a mask and everything like that but have that opportunity.

>> We are down to the last three minutes, so the last question, I know it is going to be hard because it is going to be about yourself so try to limit on how long, how much you say. But a 30 second elevator spiel as to why are you an amazing parent. What are some of the strengths that you have?

>> Dan Lajole: Do we have to get our kids to chime in on this one? [LAUGHTER] Um again of course I think I'm an amazing parent. You know what, I communicate with my kids, but you know I'm their dad. I tell them to turn the Internet off, I, you know, at the same time will talk with them when their friends are hurting their feelings, so I think I'm a pretty good dad and you know I guess see when they are older how they turn out. So far so good.

>> Amanda Hearn: I think could just having the balance of structure but still fun, because it's just me I'm always good cop and bad cop so um finding that balance I think is what makes me an awesome mom.

>> Edward Faruzel: I think many, many people look at me as a DeafBlind father of three children, three beautiful children and I think they are inspired to see that I can do it and we can do it and there is just many positives so I think that's very, very up lifting for my children to see that to be proud and I'm a proud father.

>> Hi Marina it is Ryan from CNIB, I know I didn't say much but I would love to chime in, I'm a father who is blind with an 11 month old and I think I speak for everybody when I say that we're all good parents because we love our children and that's what they need most.

>> Dan Lajole: Absolutely.

>> Marina Dotzert: Thank you for adding that last minute comment that's a wonderful way I think to kind of bring our Webinar to a close. So thank you Dan, Amanda and Elio and Ryan for taking the time to speak with us today and getting a glimpse into your private lives it is a pleasure to hear you're thoughts, thank you Edward for leading our talk today as well. Finally thank you to everyone for joining us, we hope you found our discussions today valuable. If you do wish to provide any comments or feedback about today's Webinar, please don't hesitate to reach out by e-mailing [access@kitchener.ca](mailto:access@kitchener.ca). There is also great organizations in our region looking to help you out if you do have any questions or want some information. A few of those great organizations have actually helped us create this event today and Bridges to Belonging Waterloo Region, Canadian hearing Services, Canadian National Institute for the Blind, City of Kitchener, City of Waterloo, Community Support Connections, Independent Living Centre of Waterloo Region, Kitchener Waterloo accessibility again captioning, video interpretation and transcription services were all brought to you by City of Kitchener and City of Waterloo and a video copy of this Webinar will be made available on our Kitchener Web page at [Kitchener.ca/inclusion](http://Kitchener.ca/inclusion) where you want to sign up for this Webinar. Before we sign off there is just one more Webinar left in our Life Made Accessible series. Tomorrow we will be hearing some Perm stories from individuals who experience disability. We would love it if you could join us from 1 until 2 for more information you can register at [Kitchener.ca/inclusion](http://Kitchener.ca/inclusion). Thank you everyone for joining us and I hope you have a fabulous day.

>> Dan Lajole: Thank you.

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>> Bye, thank you.