

LBS3E5 Living Deaf - And Blind - With Barbara Davis

Transcript

Naomi

Welcome to Living blind. I'm your host Naomi Hazlett, and this podcast is brought to you by BALANCE for Blind Adults located in Toronto, Canada. This season of Living Blind is sponsored by Accessible Media Incorporated. Here at Living Blind, we explore the perspectives and lived experiences of people with sight loss, and delve into barriers, challenges, and real life strategies for living life to the fullest. We often hear about how blind people are a minority within the population, who within that broad spectrum of blindness there is an even smaller minority of folks who are born with or develop later in life, both hearing and vision loss. This is known as deaf blindness. We haven't talked about living with deaf blindness on our show before – well, until now! Joining us this month is Barbara Davis.

Barbara was born with Usher Syndrome a condition in which a person has both partial or profound hearing loss in addition to progressive vision loss due to the eye condition known as retinitis pigmentosa or RP for short. Listeners may recall previous guests on our show who have also talked about having RP. Barbara got her start in advocacy work in 2000, as deaf-blind intervener services were losing funding and faced being dropped as a service offered under CNIB. She founded the Emergency Intervener Services Program in 2013, and is currently working with the National Association of Deaf-blind America on a week long deaf blind conference to take place in 2030, in Atlanta, Georgia, in honor of Helen Keller's 150th birthday. Every spring, Barbara can be found crocheting squares for the yarn bombing for Deaf-blind Awareness Month. When she's not devoting her time to volunteer work, she's busy spoiling her grandchildren in her home in Burlington, Ontario, and exploring the outdoors with her husband. And that's one of the biggest things I gathered during my conversation with Barbara, is that when her mind is set on doing something, there's no stopping her. Also for this interview, Barbara joined me with her intervenor, Rosita Foley. When I asked a question, Rosita use tactile signing to communicate the question to Barbara, who proceeded to sign the responses back to Rosita. Tactile signing is a sign language that has the messenger signing on the palm of the hand of the receiver.

As Rosita received the message from Barbara, she spoke the words to me. So of course, there were some pauses, and Jeffrey has kindly edited those out so that when you listen, it will sound just like an interview with a person who uses their voice to communicate. I truly enjoyed interviewing Barbara, and it gave me a deeper appreciation for how important intervener services are for the full inclusion of people who are deaf blind. And now, let's get to it!

Today, I'm joined by Barbara Davis. I'm going to let Barbara introduce herself today. Barbara, can you tell the listeners a little bit about you and you know who you are, your journey with vision loss and anything else that would be good for us to know about you?

Barbara

Okay, um, yes, I was born deaf, and and visually impaired it's called Usher Syndrome B1. Which means that I was born deaf and also have RP and I continue to lose my vision as I progress in age. In my family, there's five of us. And I tried to I'm involved in as much things as I possibly can. And I enjoy trying to enjoy my life as much as I can.

Naomi

And Barbara, for today's conversation, I believe you're joined by an intervener is that right?

Barbara

Yes, correct. Right. On my interview, I need to have an intervenor because I have no vision fields and I cannot hear. So for reading or searching things or anything that's not accessible to me, or leaving the household I need to have an intervenor because I'm not able to walk like straight. I have really really bad balance and perception of the area around me so even though I think I'm going straight a lot of times I'll start going a little crooked and you know, even just in special like areas just around my house outside of my house I'm easily disoriented. So yes, I need to have an intervenor with me at all times to get around outside of my household.

Naomi

That's an interesting place to start because I from my understanding I thought an intervenor or was someone who helped a person communicate but you're saying that your intervenor or also helps you navigate around the community?

Barbara

Yes, absolutely. Both. You know, when we go to stores, they'll give me the visual field of what's out you know, what to what I'll ask her what to look for. Or at the doctors are appears for communication as well, I usually, for special doctor's appointments or hospitals, I like to have specific intervenors that are really good at sign language and they're able to make sure that my message is clear and precise. But then I can use other intervenors for regular like outside exercise, walking or grocery shopping. Or but at home, I'm completely independent - I don't need an intervenor for anything. But sometimes, you know, I'll get a piece of mail or something like that, and I'm not able to, obviously see, so they'll help me like organize my files and put things away. in that concept, otherwise I'm completely independent in my household.

Naomi

Right! So it sounds like an intervenor can do a lot of different things. But at the end of the day, there's a lot that you're doing on your own as well.

Barbara

Correct, both, I'm the boss, I tell the intervenors what to do. And sometimes also with technology, right? Like we depend on technology, but a lot of times there's, they don't work properly, and there'll be pop ups or kinds of things that I'm not able to fix or get out. So my intervenors will need their eyes and ears to actually change that. Same thing with pairing and di-pairing Bluetooth, because I'm not able to use obviously voiceover. So that's where my issue lies. And a lot of times, it'll be pop-ups that I'm not able to read on my Braille display. So I'll need intervenors' eyes to help me navigate my technology at times. So I personally, that's why a hearing intervenor is very helpful for me is they can then they can use their voice. And there's a lot of clients that actually prefer having deaf intervenors with them, because they can understand better and they can communicate better with and feel more comfortable with them and their own environment, which I understand. But for me personally, I like having that voice

to make sure that there's clear information and, and that my message is getting across clearly. You know, a lot of times there's miscommunication. That's one of the biggest issues between clients and intervenors. But I find that very important.

Naomi

So I want to take a step back for a minute and ask you about Usher Syndrome. So you said that it affects your vision and your hearing? What was that like? You know, kind of starting from growing up to adulthood? And how did it affect your everyday life?

Barbara

Sure, yeah, certainly Usher Syndrome. That means that you are deaf and you have RP. So people who are deaf, sorry people who are hearing have RP. But Usher means that you are also deaf and blind. So you have both. So our retinal Pigmentosa. So where your eye, and the retinas the cells in your eyes, become damaged, and start to, your visual field starts to tunnel and goes away completely. So that's the disease, it's, it's killing at the retinal cells in your eyes. And the rods, that area in the cone, the three areas those cells are your is what you see, right? So those are damaged by the disease. And it's a slow, progressive visual disease. And that's why they're working on stem cells now to try to fix those stems that are destroying the vision, the vision to repair them or get fixed. I don't know, I hear there's some trials in California. So hopefully, that's something to look forward for in the future. But it's being deaf and blind. So when I was little, my parents weren't aware that I was deaf, they would call me when I was a baby. They were trying to call me and they went to the doctor and they said, you know, Barbara was not answering. So the doctor would say, ... so my parents said I was deaf. And the doctor said No look, look, and they would stand behind me and clap and I would turn around. So they said she's not deaf. But they didn't realize that when they were clapping the air would like hit my hair, so I would react and turn around. So finally, I went to go get actual hearing tests done, and that's where they identified that I was deaf. And as I progressed in age, around one or two, my mom realized that I just didn't navigate so well visually. But it was just small little triggers so they didn't really notice. When I was five though, I was telling my mum things, because at night time, I'd say "I can't see I can't see". So my mom actually took it as, as I was scared of darkness

instead of like just actually not being able to visibly see what was around me at nighttime. Laughs - So they actually, in the beginning, they would hold my hand and realize that actually, as I progressed, that that just started to get worse and worse. So when I was eight, I went to the doctor and I think that's when they actually were able to identify that I had a visual impairment but they never told me specifically. My mom at that time decided not to tell me because she wanted me to just live life as every other child. But I actually believe that was the mistake, because a lot of times I did a lot of risky things that I probably wouldn't have done if I realized that my visual field wasn't as the same as my brothers and sisters, right? So like riding a bike, you know? So I would have a tricycle but my mom would not let me go on, on like a single bike like. So I disobeyed her and said, "you know what, I'm gonna take my friend's bike, and I'm gonna go for a bike ride on her bike!" And I went for a bike ride. And they kept doing it without my parents knowing and saying, like, look, I did, I figured this out, I did on my own, I showed my parents, they could see that I was not going straight. I thought I was going straight, but I was just like weaving in and out like on the sidewalk, because I just couldn't. So at that, at that time, still, my parents didn't tell me that I had a visual impairment. They just said no, that I shouldn't ride a bike because it's dangerous. But when I was 15, I continued to ride the bike independently without their consent. But when I was 15, I actually ran over a cat. And that's when I realized that ... I didn't hurt the cat, I just realized that that's.... I didn't see the cat was there. And I don't know why the cat didn't move. But I just ran it over. The cat was fine. But I just realized that that's not right. There's something wrong. And I was actually playing with a friend, and my friend was trying to get my attention. She was running beside me, and you know, when you're running outside, and you're thinking you can like run and talk to your friend? I couldn't do that. I wasn't able to like run, I'd always have to stop and talk. And I remember my friend at the time, realized that that's really frustrating. Like, "I asked you a question three times, and you're not answering me". And at that time, I said, "no, wait, hold on a second, I didn't even see that you're asking a question. I didn't know". And my friend said, "can you see out of your side vision, like, can you see over here to the left of you?" And I said, "yeah, I can see everything, why would you ask me something like that? That's ridiculous." She said "no, I don't think you can see from your side, because I'm running beside you and you're not seeing me asking you questions and signing to you. So maybe you should have that

looked at like, maybe you should talk to your parents." So at that time, I ran home, I was bawling my eyes out. And I ran home and I yelled at my mom and I said, "what is happening!?" And I realized that it just hit me. And it really hit me too, all the things in the past that I wasn't able to do, or I couldn't do like everybody else. And now I understood why, right? I just thought my eyes were the same as everybody else, I had no idea that my eyes weren't the same and my vision wasn't the same as everybody else. And at that time, my sister also said the same thing to my mom that that "trying to protect her in a way wasn't, wasn't good," because I could have been hit by a car, you know, because I was just running around following my friends, just doing what everybody does, right? Without any awareness to like, actually move my head further to the left to right to ensure that I can see my whole visual field. So after that, I was actually pretty depressed for about a week. And then I started to change my vision, my thoughts and tried to make try to make it a positive thing instead of a negative thing, you know? It's been a struggle, for sure, right? Especially, like, after I had my own children, you know, like my own kids would pick on me, and they would like they knew where my visual field was. So they would like sneak around on the floor and crawl and I used to hate that! It's like, I can't see that! Right? Now that they're bigger, they get that they, that was very, a very wrong thing to do, you know. Laughs. But I know now, obviously that I'm older, that I can't babysit my grandkids, because they'll pull a lot of tricks on me. So I just like to visit them keeps them from, just nice, little visits, say hello, but I can't actually watch them. So now I'm taking time to myself, and focusing on myself and doing things that I want to do in my life.

Naomi

Wow, that's an incredible story! I'm wondering, well, I have a lot of questions. But one thing I'm wondering about is once you knew that you had vision loss. What happened there? Did you get any help for that? Did you learn any new skills? Can you tell me a bit more about that?

Barbara

No, I didn't get any help at that time. Later in life... So let me think. Yeah, so I was 20 when I moved to Toronto, and that's when the CNIB, that's the first time I heard about CNIB Intervenor Services. But it wasn't given the information wasn't

given to me clearly. And you know, like, "they'll help you do this, they'll help you do that." But it just, I didn't really understand it. They didn't really explain what an intervenor was, what their purpose was, you know, they're like, they help you to guide. They help to communicate, they just, they do this, they do that. But like, it just didn't, it didn't feel comfortable. So then about six months later, I met another volunteer actually a volunteer, and that person volunteered on their own. They were 25, and you know, they were just, they would take me to the grocery store just helped me a little bit. That was you know, when I was 25 Sorry. And then when I lived in Oakville and in Burlington that's when I actually received intervenor services from the Hamilton area. That's when I was 25, that was the first time I received intervenor services and I learned what it like, what it actually is, and I went to to the camp the Lake Joe camp. I was scared there, because I saw a lot of different disabilities that a lot of different and I just misunderstood, like, I thought that once I was to lose my visual impairment, that that meant that maybe I would also have other disabilities that will come along with that. And no, they showed me that no, like, there's all different spectrums, there's different visuals, and there's different disabilities as well that they have added disabilities as well. And that's when I met my first like, born deaf blind individuals, which I'd never met before. So that one was a shocker, because at that time, my visual field was a lot different. And I hadn't been involved in the deaf blind community. So it was very overwhelming, but it was educational. And as I grew on, you know, they, they were trying to encourage me to, to take cooking lessons and O and M, and those kinds of things. But at that time, I like to do things on my own, I like to do things on my own way, you know, I still continue to this day to cook I've never, I never follow instructions, the way that they do, you know, doesn't work for me. I like to do, you know, the things that I like to do on my own. You know, a lot of times they tried to, to encourage you to use the microwave, but for me, like actually, I'm prefer to use the stove, you know. My husband luckily does most of the cooking for us now, he likes to do like a lot of advanced cooking that I wouldn't be able to do. So my husband has taken over that task, which I quite enjoy thoroughly. So I'm in charge of cleaning. So you know, we're a good team like that. He'll do the cooking, I'll do all the cleaning, right. And that gets me a lot of different meals that I wasn't able to do before. So it works out for both of us.

Naomi

I was going to ask you what your favorite recipe to cook is. Maybe you can tell me one that you used to cook back in the day.

Barbara

Shepherd's Pie, actually, but I'd make a chicken. And I still make that. Um, but what I can't do is like I can't cook steak, for example, like, are on the barbecue, I'm not able to use the barbecue. So my husband will do that for me. But like I'll do fish in the stove, I do that. But now that my husband's kind of like taking the reins, you just kind of mostly does all the cooking. But I'm still able to do it if I want to. He kind of let me stop, it's been a while because he's been making a lot of he's been taking charge of the menus. So I can't really remember. Let's say yesterday, we as a team, we made a coffee cake. But we did it together. And but we put like a cream in the middle, like an icing. And so we actually did it together. He like I made the dough part. And then he told me what to put in the middle part like the ice icing, I guess. We were following a recipe on the iPhone. But subtracting the technique, my technology froze, and I wasn't able to use my real display. So he read the recipe for me, it was delicious actually. It was really, really great. I strongly recommend it! I really enjoyed it. Or like cookies, we made turtle cookies together in September and October. I always make it for my grandkids, they love it. So I always said like I can't do it all the time, it's a lot of work. Also expensive, right? Candies, little turtle candies, you have to chop them all up. And they're very expensive. So I usually wait until the fall time and I do that for my grandkids who are always asking for that all year round. You know, so we don't make desserts often. But it's a nice thing to do together sometimes just to share with my family.

Naomi

I think something that struck me in hearing your latest answer, is this idea that on the one hand, you seem like a very independent person, you know, you're the boss, you used to ride bikes, you know, you kind of don't let people stop you from doing what you want to do. And one thing I liked hearing about how you're cooking with your husband is that it's not always about getting help, whether it's from your husband or an intervener. It sounds to me that it's more about working as a team, right?

Barbara

Absolutely, absolutely! Yes! Teamwork is important, right? I tried to keep like, intervenors, and husbands are very different, right? So I don't want to depend on my husband at all really, you know, I work as a team, but I don't want to put any added stress or I want to give him relief, like as a wife would in a regular relationship right? A wife that can go out and do the groceries and do whatever they want and not need to rely on their husband. So that's where I really rely on the intervenor to be able to give my husband a full break and allowed me to be independent and provide.

Naomi

I think this is a good time to mention that you founded an emergency intervenor program. Can you tell us a little bit more about that?

Barbara

Yes, absolutely. That was a struggle when I joined it In MCSS, a few years back, I had a lot of great ideas that I brought a lot to the table. And, you know, I was the only person who was using Real Display at the time that was fully blind. And at that time, I was saying we really need intervenor services. And they kept saying, Yes, we have intervenor services like emergency intervenor services. But what I was trying to find is something different, like something that's not short term, that's something that's permanent, like a setup system. And at that time, MCSS wasn't aware that there wasn't something like that and set in place, they, it wasn't really ever discussed. No one advocated for that. I continued to fight every single meeting, I kept saying, this is incredibly important to have access to emergencies, when a deafblind person is in an emergency situation. So it was set up finally, in 2013. You know, because anytime I had an emergency, I'd always have to contact my children. And that's not really fair, if my kids were working or doing something, you know, like, I shouldn't have to depend upon other people. If I have an emergency, you know, I need to be able to access whatever I need on my own without depending on other people. You know, my family was very proud of that. So it actually came into fruition in 20. Oh, sorry. 2000 2001 2000, I believe was when deaf blind, so this is a different... deaf-blind services was having issues in 2000, and they were not going to be part of CNIB anymore. And that's actually where my first advocacy tastes came from. And I

started to fight to try to ensure that deaf-blind services continued in that office, and I started fighting. And that's I made a lot of mistakes. And I learned from that. And I've grown from that, but it's definitely given me a taste for it. So now I joined everything I can, you know, going with, like all kinds of disabilities, not just deaf-blindness, physical disabilities as well, making sure that everybody has access in any which way. I'm on multiple boards, I'm on a couple boards in the States as well, Canadian boards. And now I'm actually in part of the committee in the United States. And we're setting up a conference, I will be the head of the conference in 2030. So eight years from now to set up this conference, to plan. So that's, that's exciting! That's a new thing. They took me! - I'm the only Canadian person on their board. And they've seen what a great leader and what I've been able to bring to the table so far already in the last year that I've joined their committee. So why not, you know|? I don't want to sit around, I want to I don't want to get bored, I want to be able to participate and be a contributing member of society. Just now in June, actually, I just went to Helen Keller's birthplace. I took a tour around, it is beautiful. And I met a lot of people. And you know, that's when they invited me to be a part of their community. And that's where we started this idea about, like. Sorry, I met the couple there that started on their own committee. They are both deaf-blind, a husband and wife. They're both deaf-blind, fully deaf-blind. I thought, wow, like that's incredible! Like the two of them, that was really inspiring to see that, you know, that teamwork. And from there, it sparked the need to need to continue fighting.

Naomi

I want to know more, but I just want to take a step back because we have people listening from all around the world, and they may not know the CNIB or the MCSS. So, I know, that the CNIB is the Canadian National Institute for the Blind. Barbara, can you let us know what the MCSS stands for?

Barbara

Oh, yes, good point. DBCS is Deaf Blind Community Services. And I'm still a member of the board since 2010 until now, and I'll continue to advocate for funding for deaf-blind individuals.

Naomi

Great, thank you. And you mentioned that you have a conference coming up in 2030. Can you tell us what the conference will be about?

Barbara

Yes, I just know a little bit of details because we're just getting started. We just started in June. The plan is in 2030 in Atlanta. What it's an hour flight out of from where Helen Keller's birthplace is. The idea is to have a weeklong conference. It's gonna be NADBA, ... NADBA? So to be National Association of Deaf Blind America. NADBA. Laughs Trying to remember all the acronyms, its hard, right? So yeah, so I'm a member. SO yes so I'm on the committee, so now we're starting our first conference there. So we're planning it to be a weeklong conference. We're hoping and it's also going to be Helen Keller's 150 ... birth year, I guess. So we're going to try to plan it all in the same week and have multiple events in the in like a hotel area. I just need to make sure that it's all accessible and all that. So I don't really have many details. But in 2025, I will have the set place of where it will be the dates and times and I will let the Canadian Helen Keller center, advertise it through their means where they have contacts to let all the deaf-blind individuals know.

Naomi

Well, you have to keep us posted! And if you have any information about the conference, please let us know. And we can put it in the show notes.

Barbara

Yes, absolutely, I will.

Naomi

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Naomi: So we've been talking a little bit about your life outside of your husband and your kids, and I want to know a little bit more about your journey as a mother, can you tell us a little bit about how that happened? What was maybe

different for you as a deaf-blind person? Just what was your motherhood journey like?

Barbara

My journey? Sorry, intervenor clarification. Yes, got it. My life as a mother is hard. Because children are sensitive as well, right, and you get upset, especially seeing their mothers vision fields that decrease and not understanding that. And, you know, I remember that growing up, my kids kept saying, "I don't want you to continue to get more blind," you know, as they saw that it really affected them. And I had to explain to them all the time that this is not something I can fix, there's nothing I can do about this, we just need to enjoy that the time that we have, and try to make the best of it, you know. Now that they're older, they understand that, but when they were children, it was really, really, really hard. You know, and like now, there, there seems to be some positive news coming right from the STEM fields idea, so that's also encouraging as well, you know. But a lot of times my family now that sees that I'm completely blind, they can they they're inspired by that too, as well, right? To see the positives and how I'm able to do anything, you know. In 19, ... sorry 1998 to 2002, I wanted to get my high school diploma, I didn't have my high school diploma, I had my children when I was really young. So I never finished my high school. So I had a six and eight year old, and then two teenagers a 16, and an 18 year old. And I went back to get my high school diploma. My husband would work overnights, and I had my four children. Ugh, that was a struggle! I tried my best, but I made it I continued to develop and I continue to increase on my, my literal knowledge. And you know, my homework and my math and my English, you know. Cause I found it very frustrating with my children, and I wasn't able to help them and I wanted to be able to help them at school. But I was completely exhausted, I will tell you that! My teachers were shocked that I was able to make it through the day. But I did it. It took me two years, you know, with four children and I graduated, I got my high school diploma. I upped all my grades, you know. And that's with four children, four young children. So I really can say that you can do anything you put your mind to. That's the important thing. And it's important to be a good positive role model for your children, right, your children seeing that, I think that was very influential on them too. Seeing their mom go back and better herself and be able to do anything, regardless of whatever comes along your way.

Naomi

That's incredible, hats off to you! That's. ... I can't imagine how much work it was being a mother to four kids and going back to school. So I'm just in awe. How are they this...

Barbara

Yeah, it was a very long day, because it was a full day school day of school 8:30 to 4:30 right? So that is on top of my parenting.

Naomi

Wow! I'm thinking about people listening into the podcast, who may have a disability and are thinking about being a parent, but might be feeling a little nervous about it. Do you have any advice for them?

Barbara

You want children? If you're... just go for it. Just try to be positive, that's the most important thing, you know? Like there's struggles for sure, right? It's important to have good supportive teamwork and support rehab, whichever, as a partner or as your family, you know, because it's, again, hard and especially with what your visual field may be. And it is challenging, that's for sure. But you would just do the best that you can with the tools that you're given and you just try to continue to improve on that. You know, But it's, it's not perfect. It's not great. And communication is very important, right? Because kids are hard. Kids are hard. And they get frustrated a lot. And they, they're just their emotions, right, they have a lot of emotions and you try to be as positive as you can. But that's hard for your child to see that you're deaf blind at the same time, showing them how successful you are. It really helps them as well. We live close to Milton. They have a deaf school, there's called E.C. Dury. And I actually approached them. They had four children who had Usher syndrome that lived in Mississauga, and I wanted to help and talk to the parents as well and talk to the children because the children were really having a hard time understanding and accepting, you know, their disability, right? But at that time, I remember that the teachers didn't they, because there's a confidentiality, all those kinds of things. But I just wanted to show them that I was able to show them to see, look, I'm a successful woman,

I'm married, I have children, I'm able to do what I need. And I have my own family, you know, like being diagnosed with Usher Syndrome isn't, isn't as debilitating as you would think. Like, I'm just a member of society as everybody else. It just takes me a little bit longer to do things, you know? Like pitying and feeling sad for people, that's, that doesn't help you, that doesn't get you anywhere in life, right? So that's, that's, that's frustrating. But you just got to show that you can do anything you want, that you put your mind to.

Naomi

I think that's a good point to make, in terms of the fact that there are a lot of myths out there about being deaf-blind or having a disability. I think a big one that able bodied people have is being deaf blind, that there's just so many barriers and things that you're not able to do. So I like how you constantly tell the world that "no, that's not true... I can do whatever I want". Are there any other myths that you'd like to bust about being deaf-blind or disabled, or just in general?

Barbara

Yes, I know, for driving, right? So people who actually are deaf, but I'm deaf-blind, obviously. But there are deaf people that were feared of not being able to drive right? Like I have to make that that acceptance that I'm not able to drive. That's when that's, that's a hard one. That is definitely a truth that I can't see, I can't drive. But we need to find other ways to navigate ourselves, you know, to get out and around. You know, it doesn't mean that I'm stuck in a moment, I'm not doing anything like, you know, there's taxis, there's wheel trans, there's intervenors, I have intervenors that taking me anywhere where I need to go. So there are other modes of transportation, I remember people thinking that mean, not being able to drive would mean I'm not being able to do anything, and I'm home alone all the time, right? But that's not the case. Like, we need to think outside of the box, right? And try to find different ways and that will help you cope, and that'll help you try to stay positive, right? And that's where I participate in anything I can like volunteering. I volunteer wherever I can. Obviously, I would rather be paid employed, but it's really, really hard to find employment as a deaf-blind individual, you know. People think that you're not able to do things and that's really frustrating. You know, my mom saw that and saw that for my future and didn't want that for me. And she didn't, she didn't want to pity me. So she

actually I think that that was the way I was raised. I was I was raised to be able to do things on my own and fight for myself. And, you know, in the end about the biking, right, like, I stopped on my own, that was my own choice, because I realized I had to obviously, but I did it even though the people around me said I couldn't. Just remember everybody has different struggles and different gifts, right? And different skills, right? Some people are incredibly great at biking. I don't know, some people are really good at fixing things or doing anything with it. And not being able to see like, every single person brings something different to the table, every skill is needed. And we just as we all work together, we can do that together.

Naomi

Mm hmm. For sure. I like your point around the fact that everyone is no matter whether you have a disability or you're able bodied, everyone in the world is good at some things and maybe not good at others. And it's the point is about using our strengths to help each other.

Barbara

Absolutely, that's right.

Naomi

So I have one more question for you for today. One that we haven't really talked very much about. But I think at the beginning of the show, you mentioned that you use a braille display. Can you talk a little bit about the technology that you use in your everyday life?

Barbara

Yes, I use a Braille display since 2014. Before that, I was able to use computers with ZoomText. But from 2014, I was unable to see any more so I can transitioned to a braille display. So that's how I access all my emails and news. And there's a lot of things that are still not accessible, which is really frustrating. I use an iPhone, and every update that comes any iOS updates that come there's always some sort of glitch that mess up my braille display and freeze it, which is incredibly frustrating, you know, a lot of times because then you need an intervenor to help you because it's frozen or stuck, or there's a pop up again that

I can't see or I'm not able to navigate. So I'm hoping that one day in the future, iOS will just be smooth sailing. iOS seven, I remember was great. Now we're iOS 14. And it's, it's a, there's always a problem. So that's frustrating. But like I use it to read, I read, I read a lot of ebooks on my braille display. I read the Bible. You know, I navigate the Internet on my braille display. So I obviously prefer to read with my eyes like it would be a lot quicker. Braille is slower, and it freezes a lot. So I'm dependent upon it, but it's a skill that I've gotten much better at.

Naomi

Can you tell me when you learned to read braille? Because I know you mentioned you had some vision when you were younger. So when did you start learning braille?

Barbara

I was very behind in braille. Because I didn't want to think about it. Honestly, I was in denial, and I was avoidance. And I was like, no I can I can see, I'll be able to see for a long time, I'll just work through it. So I kept putting it off and putting it off. And then I just might, I couldn't as much as I wanted to I couldn't. So I had lost my vision. And I worked with a teacher to try to do braille, with the books with the large print books. And but I hadn't used the braille display just the regular braille books. But I found that the way that they were teaching you, it was really like it like took a long time. And it was, so I went on my own and I emailed some, some people like, deaf-blind people. This is regarding sorry, how to navigate with a braille display and how to use commands. So I did it on my own. I figured out the braille display completely on my own, and how to use the commands for the iOS. Because the way that they were trying to teach you is really, really long, and I would forget all the keys to remember. So I do things better on my own, figuring it out for myself. So also depending on other deaf-blind, as well, asking them questions, and people who know from the basic. Symbols? Yeah, there's some symbols on braille displays that I don't know yet, like brackets, and like, you know, I know most of them, but some of them that come on long, and I don't recognize them. But I don't find that important. But I know the letters and all the big stuff. So that's the important one.

Naomi

Hmm, that's neat that, you know, I'm again, impressed because like, you mentioned about getting your high school diploma. It just sounds like you're a person who sets your mind to doing something and will get it done one way or another.

Barbara

Yes, absolutely. I was supposed to finish obviously, young, but I had a lot of problems in school and I wasn't able to, to access schools the same way as everybody else did. I found it very frustrating. I was actually depressed. I, I left school when I was 18, I was a drop out. I have a lot of stress a lot of headaches. And then I realized later in life that you know that people would pick on me and bully me because they didn't understand what my visual impairment was, you know. And now, I'm older and I understand, and I don't let those kinds of things affect me. And but when I went to adult continuing education services, everybody there was adults, and so that I found a much more welcoming environment where I was able to succeed and get everything I needed.

Naomi

I'm glad even though it took a little while you got to where you wanted to be at the end of the day.

Barbara

Yeah.

Naomi

I think that's almost all the time we have for today. Is there anything else you want people listening in to know about you or your journey or any advice you have for them?

Barbara

Okay, I want everyone to know that if you have children who are deaf-blind, don't be scared. You know, if you hear that diagnosis, don't be scared, they're... everything else is fine. It's just they're able to do anything that everybody else is, is able to do it just they might need some help or it might take a little bit longer. What's most important is just to give them lots of love. And strongly just believe in

what you can, what skill sets you have, you know? Again, as I said before, we don't all have the same skills, but we all do have some skills that can help us and if we work together with other people, we can learn from each other and improve continuously right? And to allow them to be involved in everything that they possibly can... like don't be worried.. don't hold any barriers... don't hold them back. You know, the first time I joined advocacy, I made a lot of mistakes. And I learned from that and then look at where I am now. Right? It takes years of experience. It takes time. You know, it's just like, the braille display, right? Like, I started learning, and I put it off as much as I could, but once I did, it opened up a whole new world to me, right? So just be involved in the community, don't be scared, you know? Join things, you know... any committee. Join boards, you know, even if people are saying you're blind, you can't do it. Like, no, you can figure it out, like my brother. He's deaf-blind, and he plays hockey! He's a goalie. So you know, like, it's hard for him, but they use a special puck. You know, they said to him that he should have stopped when he was a teenager, but he didn't. He kept going as long as he could and there's nothing wrong with that, right? Like he, you know, I, I played baseball, I tried to play baseball, but I can just be ball all the time. But you know, that experience was great, just being part of a team and just being able to meet people. And you know, so I found that that didn't work for me or swimming, right? Like I love swimming. That's something I do all the time. Or reading... reading is something I love, and that's opened up my mind to so many different things as well, right? I've learned so much from that. The important thing is not to think that "I can't". That's important thing is that "I can". Try to be positive and just try to realize that you can do anything you want. It just might have to do it a little differently.

Naomi

I think that's great advice! Well, thank you so much for coming on the show today, Barbara. If people want to know more about you and your work, where can they go to find you?

Barbara

I don't have social media or anything like that. But maybe that's something that I can start in the future. I'll talk to my intervenor and see if we can set something up so people can contact me.

Naomi

Alright, sounds good. Well, thanks again. It was such a pleasure getting to know you, Barbara, and I wish you all the best on whatever journey you set your mind to next.

Barbara

Thank you. Thank you! Absolutely.

Jeffrey

Let's let Rosita take some credit here.

Rosita

Hi, my name is Rosita Foley, I work for the CNIB deaf-blind Intervenor Services. And I'm Barbara Davis' Intervenor for today.

Naomi

We've got lots of links to resources around deaf blindness in this episode's description, including where to find intervene or services, deaf-blind organizations across Canada and the United States, more reading on Usher Syndrome, and Barbara and Rosita's contact information, so you'll want to check those out. Well, we hear the music, which means it's time to wrap up yet another episode of Living Blind. We're glad you can join us! I really hope that you enjoyed this interview with Barbara as much as I enjoyed doing it for you. Special thanks to Barbara Davis, Rosita Foley, producer Jeffrey Rainey, Executive Producer Deborah Gold, and the entire team at BALANCE for Blind Adults. Feel free to subscribe and give us a rating and review on whatever platform you're listening on. And don't forget to let us know how we're doing! You can find us on Facebook, Instagram, YouTube and Twitter, by searching BALANCE for Blind Adults, and chat with other listeners in the Living Blind listeners Facebook group. You can also email the podcast with any comments, questions or suggestions you might have, at LivingBlindPodcast@BalanceFBA.org. For more information about BALANCE for Blind Adults and our programs and services, or to access the show notes and transcription of this episode, please visit us at

www.BalanceFBA.org. I'm Naomi Hazlett, and this has been Living Blind and Deaf with Barbara Davis. Thanks for listening.

Deanna Carruthers

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