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SPEAKERS

Ryan Fleury, Lis Malone, Rob Mineault, Dr. Linda Mamer, Speaker 1, Steve Barclay

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R **Rob Mineault** 00:05

Hey and welcome to another episode of AT Banter,

S **Steve Barclay** 00:26

Banter, banter,

R **Rob Mineault** 00:29

Hey, this is of course, the podcast where we talk with advocates and members of the disability community to educate and inspire better conversation about disability. Hey, my name is Rob Mineault, and joining me today. Mr. Ryan Fleury,

R **Ryan Fleury** 00:48

I'm RF today.

R **Rob Mineault** 00:52

And and listen to that sound, that gentle laughter. That must mean that joining us for the first time in 2025, it's Miss Lis Malone.

L **Lis Malone** 01:03

I come bearing tariffs.

R **Rob Mineault** 01:18

We'll get into that. Don't worry. Look who else it is. It's Mr. Steve Barkley,

S **Steve Barclay** 01:23

Where?

R **Ryan Fleury** 01:25

Over there.

R **Rob Mineault** 01:29

Listen, this is a momentous occasion. This is the first time that we're actually all together in 2025.

S **Steve Barclay** 01:37

Hooray to us. Are we ever really all together though?

R **Rob Mineault** 01:40

Hail, hail. The gangs all here. Well, that's true. What a week. But yeah it's good to good to have Lis back. We were just lamenting, I think, last week, that we hadn't seen you at all this year. So it's nice to have you back, even though I'm not sure we can afford you, being 25% more expensive.

L **Lis Malone** 01:59

Right?

S **Steve Barclay** 02:04

Allegedly paused for the next 30 days or more.

R **Ryan Fleury** 02:08

Yeah, well, they didn't put a percentage, on US correspondence.

R **Rob Mineault** 02:14

Well, 10% on oil, or some 25% everything else. I mean, we're, again, it's the math lines up, because again, 25% of nothing is nothing.

L **Lis Malone** 02:24

I think they pay you for taking me. I think it's like a reverse tariff.

R **Rob Mineault** 02:31

Please take her.

L **Lis Malone** 02:36

I'm a woman without a country.

R **Rob Mineault** 02:40

Yeah, we're shoring up. We're shoring up the border now, so I don't know it's gonna be tricky to get over here.

S **Steve Barclay** 02:48

I saw some really funny info on the tariff front there, because, you know, Trump said, oh, you know, Mexico and Canada back down from everything. So the the 10,000 troops that Mexico committed to the border. There's already 15,000 there, and the $1.3 billion that Canada said they're going to spend on the border that went through in our last budget, which was like last year. So basically they got Trump to back down by doing what they were already doing.

L **Lis Malone** 03:28

Hey, it's all about posturing, right?

R **Rob Mineault** 03:30

Yeah, it pretty much is. You know, here's what I'll and we'll, I promise audience, we won't. We won't dive too deep into this, because you're probably the board already. But what I will say, here's a silver lining to this whole thing in the lead up to the to Tuesday, for whatever, where, however long it was, it he announced it Saturday. Whatever it was, a week, or whatever, where the we had these tariffs hanging over our heads. I've never felt that the country has been more united against something than in the past that week. So I thought that was nice. That felt nice, as is that there was a lot of, you know, "we are Canadian" type of patriotism, and nobody wasarguing amongst ourselves. It was kind of nice. It's kind of nice to have a common a common cause.

R **Ryan Fleury** 04:19

Well, it's kind of interesting when our own BC premier comes out and says, you know, it's easier to trade with the US than it is with Ontario. There's a problem there, right? So there's, there's an issue. And unfortunately, it took Trump and this tariff threat, I think, to get people talking about these issues we need to deal with.

L **Lis Malone** 04:40

Well, hey, listen, you're welcome.

R **Ryan Fleury** 04:46

We wouldn't have done it otherwise.

L **Lis Malone** 04:48

Listen, we're all about uniting people. Just think you could get all the Oreo flavors if you become the 51st State.

R **Rob Mineault** 05:07

I was very concerned about about what this would do to the price of Doritos. Like, does that go up? I'm pretty sure corn there, that must be a US product. It has to be,

S **Steve Barclay** 05:21

We grow a lot of corn, but probably not enough.

L **Lis Malone** 05:23

I will tell you, though, I have never seen more commercials for Canada ever. There's all these commercials that are playing there, and they're not the obviously, the tourism bureau commercials there. Hey, we're Canada, we're your neighbor up north. We do all it's all just like Canadian PR to remind Americans about how we're your friend. I think the subliminal message probably in between frames is, don't believe what they're saying to you. Don't believe Trump. But it's like, there are, you know, 17 northern United States that do that are our major trading partners. I'm like, oh my and it's just on repeat and repeat and repeat. And I said, Oh my gosh.

Like Canada is just flooding the US market airwaves to just hammer home like, we're good, we're not, we're not the bad ones in this. I'm waiting to see a Canadian like an Oilers fan, waving American flag or something like that.

S **Steve Barclay** 06:24

The other one, I was very, very disappointed to see hockey fans booing the anthem. I just don't, yeah, I just don't think that's classy at all.

R **Ryan Fleury** 06:36

Which is really unfortunate because two years ago, at the Maple Leafs game, when the mic cut out on the woman singing the American anthem, all the Maple Leaf fans stood up and carried on with the American anthem. Yeah, right. So yeah, we kind of flip flopped on that.

S **Steve Barclay** 06:51

Yeah, you stay classy. Canada. Stay classy.

L **Lis Malone** 06:57

Well, what do you expect? Which team was it?

S **Speaker 1** 07:00

It was the same day that he announced it. Emotions were high,

S **Steve Barclay** 07:06

Yeah, it was literally every Canadian venue that there was an American team playing in. As soon as the American anthem played every, every single venue, booed, it's a shame. They're still sour about not winning.

S **Speaker 1** 07:24

We can talk about this all day,I'm sure. But we should probably get to the meat and potatoes of this show. And actually, I don't know where we can afford meat and potatoes. Actually, I don't know where does the beef come from.

R **Ryan Fleury** 07:36

Alberta.

Steve Barclay 07:37

It's okay. It's Alberta.

Speaker 1 07:38

Oh, okay, good. Potatoes, though ... We get those from Idaho, so no potatoes.

Steve Barclay 07:45

What's your daddy?

Speaker 1 07:47

Ok, on with today's show. Steve, what the heck are we doing today?

Steve Barclay 07:53

Today we are bringing in one of my very dear friends and a member of the Children's Low Vision Project for years with me, until they turfed me unceremoniously out onto the street. Not that I'm bitter. Dr. Linda Mamer.

Rob Mineault 08:12

Hello, hello.

Dr. Linda Mamer 08:15

Hi. Thank you for asking me here, and thanks for Steve for that lovely and lengthy introduction. But yes, we were on the Children's Low Vision Project for years, and I traveled with Steve a lot, driving all around the Province.

Steve Barclay 08:30

I was I was often her Sherpa.

Dr. Linda Mamer 08:33

My Sherpa, especially when I had shoulder surgery. And also, you're my go to guy for any technical issues. I can send him a photo. Is this good? Is this out of date? And he'll answer me.

technical issues, I can send him a photo. Is this good? Is this out of date? And he'll answer me right away. It's just a delight to be in Steve's circle.

R **Rob Mineault** 08:53

We don't feel that way.

D **Dr. Linda Mamer** 08:56

I'm trying to build you up, Steve.

S **Steve Barclay** 08:57

I'm sorry it's not it's not going to work with this crowd.

R **Ryan Fleury** 09:02

Steve? Who's Steve? We're talking about a different Steve, right?

R **Rob Mineault** 09:07

Well, listen, maybe we can start out by just giving us a little bit of a background about yourself and some of the work that you, you do, outside of the Children's Low Vision Clinics.

D **Dr. Linda Mamer** 09:19

Well, I come from Ontario. I was born and raised in Hamilton, and I went through university and Teachers College and ended up at the W Ross McDonald school for kids who are blind and deaf blind, and went in just on a tour, and I went into the deaf blind unit there, where kids from all over Canada came and stayed, and then they would go home on like Christmas break, spring break, and in the summer. So kids from BC right through to Ontario would come. And when I walked. In there, I thought I died and gone to heaven, and I was very fortunate to have a job, get a job there, and have my own classroom of students who are deaf blind, and many of them were deafblind because of rubella, German measles, and the epidemics that were going on in the mid 60s and later. And then after that, we opened up the outreach program in Ontario, where we traveled all over the province, seeing students who were deaf, blind in their own schools. And then I did some teaching. And then I came out to British Columbia about 25 years ago, my husband and I, for eight months we were going to do maternity leave for a colleague of mine who worked in the deaf, blind outreach program here. And that was, as I said, 25 years ago, and because after the first month, I knew we were not going back to Ontario, and it's been great. So then I worked with kids and schools where there were students who are deaf, blind, and also I'm a trained teacher of students who were blind and visually impaired. So I did both those roles, and then I went away and studied. And then I've moved out of the official role of being a teacher of students who are deaf, blind, into a teacher of students who are blind and visually impaired, because there's quite a need for those positions to be filled here in British Columbia, and it's been fantastic. And one of the reasons I wanted to take on the visual impairment rule when I did was because I did want to learn more about technology, and that was back when there was just a couple of little pieces, and we'd bring all our students to Steve's office at the time and check out what was new in technology. And it was always just amazing to me what that has now led to in terms of technology for our students, from preschoolers all the way through to when they leave us to go to post secondary. So it's been a fantastic journey, and then to be on the low vision, the children's low vision project has been amazing, where we travel around the province six times a year seeing students and their families and teams and bring technology, low tech, and we do assessments with them. We are ophthalmologists optometrist and just it's, we're finding out amazing things, and it's been just a wonderful, wonderful opportunity.

S

Speaker 1 12:32

So I find it really fascinating that that you sort of have a foot in in each world, you teach kids with low vision, but you also teach in the in the deaf -blind realm. How do those two teaching methods sort of differ, and what are some of the commonalities, and what are some of the big differences in terms of your teaching methods that you have to use?

D

Dr. Linda Mamer 12:52

Well, that's a great question. When I started teaching the kids who were deaf blind, it was, of course, all about communication, and we use a total communication approach and basically use everything we can possibly think of to help them communicate. And if you think about Helen Keller and her early days of having vision and hearing till she was 19 months and then lost both, and how did she exist in the world? And my my Principal and Superintendent at the time were starting to see kids who were deaf blind, and they had to figure out, how are we going to help educate these children who have very severe vision and hearing losses? And so they went and looked at famous people who were deaf blind, and how did they exist in the world and go to school and have jobs and families, and every one of them had a person with them who was trained in communication to help them be in the world and to help them communicate directly with the world. And so John and Jackie McGinnis, my mentors, began creating this whole role, which we now call a Intervener for people who are deaf, blind, and it really started in Canada. We're very proud of that. And the training is to help a person learn how to be, essentially, in the early days, we saw it as the eyes and the ears of the person who couldn't see clearly or hear clearly, or hear or see it all. And how did we give them a voice so that they become more independent in their communication? And that became just something I fell in love with, and really got a lot of training in those early days. We really didn't know a lot. A lot of it was trial and error, and then we kept growing and growing, and now there's complete training programs for individuals who want to learn how to be interveners, for individuals. For deaf blind. So we learned about, obviously, communication and all the aspects to it when you don't have clear vision and clear hearing. We learned all about hearing. We learned all about vision, and tried to tie them all in together and it it works. It works really well. And so then we kept learning more and spreading the word around, and people from the states would come up, and people from the UK would come over to Canada to learn about this thing called intervenors. And it's one of those situations where as soon as people saw it in action. They knew immediately, oh, this, this could work. And I always think about Annie Sullivan with Helen

Keller, that the reason why that worked is because Annie didn't know what to do when she first met Helen. She she herself was low vision, and she was sent to work with this girl who Helen describes herself as as being like a wild animal at the time, and she was given two weeks to teach Helena communicate and essentially fix her. And of course, that was obvious at the beginning. It wasn't going to work. And then Annie had to figure out, how can I help this girl communicate? Because Annie believed, and this is what really has defined the field of deaf blindness and my professional life, is that Annie believed Helen had a brain, and it was her job to figure out, how do I get to that brain so that Helen can communicate? And that's really the premise of teaching these kids who are deaf blind, how to be active participants in the world. And it's evolved. We've learned a lot more, and we see a lot more children now with greater complexities, both physical, mental, all sorts of other areas, because these children are surviving, and we've adapted many of our strategies to help the children who are deaf, blind, communicate. And so that was my whole base, and then I was starting to see more kids who were visually impaired at the time with additional needs, who weren't communicating, and so they didn't have a hearing loss. But we had to figure out, how do we help these children with low vision or no vision to communicate? And so that evolved into my studies as a teacher of students who were visually impaired, and then went on from there, and I did additional studies, and then came back and did research here, and then it's just continued on. And melding those two areas together has been great, because when you understand the impact of vision loss and then the impact of not being able to communicate fully, you can really start to blend things together to help an individual learn to communicate and just to get back to Annie, Annie didn't know what to do with Helen. The only method of communication they really had at the time was fingerspelling in your hand. And if you have seen the old movies of it, you'd see Annie would just fingerspell in Helen's hand for hours and hours. She'd fingerspell poems and news and all that, Helen had no idea what it was at the time, Annie didn't know what else to do, but she persevered. And if you've seen the movie or heard the story after eight months of this, I swear Helen must have had carpal tunnel syndrome. Of this finger spelling in Helen's palm, she finger spelled water, and she was having Helen feel the water coming out of the pump and all of a sudden. And it's really one of those aha moments that I wish everyone gets at least once in their life is that Helen, while she was feeling the water, was also feeling Annie fingerspell water in her hand, and Helen put it together. It makes me emotional to tell this story. And I've told the story hundreds of times. So at that point, Annie was like, Oh, this is this. This is something. And Helen's like, oh, this means something. And Annie began to run around and touch stuff right in their in their yard, and would throw out her arm for Annie to run over and fingerspell what that was, tree, grass, whatever. And that was the whole beginning of Helen becoming a communicator. And that's really what drove the model of the role of the intervener to help people who had to have a way to communicate, but it also had to be very individualized. And it it worked. And that's what led to the whole field here in Canada, in particular, on having a person help an individual who's deaf, blind learn to communicate. So I just like to make that full circle back, because the movie is so powerful in in many ways, but it was that whole idea that Annie believed there was a brain in there, and it was her job to reach to it, and then to help Helen reach out. And she did, and it was really quite amazing. And the interesting part of intervention is it, it wasn't that Annie was the only one who could communicate with Helen. That wouldn't have been right. Annie had to help other people be able to communicate with Helen. So Helen wasn't dependent on Annie. Helen was dependent on the communication, which is a very powerful thought. And Annie did that and brought other people into Helen's life. And as we know the story, you know, she went to university, and she traveled around, met presidents and that all because she could communicate. So it's been a wonderful opportunity. I've seen lots and lots of kids have those aha moments. And it really is quite, quite a thing that never leaves you. But it, it can happen, and we have proof, and it's, it's very exciting.

R Rob Mineault 22:02

You know, we say all the time on the podcast when we're talking about blindness, you know that there's so much education needs to happen. There's so many misconceptions about blindness, and I'm sure that with deaf blindness, even more so for a lot of people. It just it blows their mind that you can even break through that, that communication barrier with somebody who's deaf, blind, do you find that? Do you find that there's a lot of misconceptions in the general public when it comes to deaf, blindness?

D Dr. Linda Mamer 22:29

Absolutely, especially if the child has additional needs, and that people haven't really looked at all the aspects of the child, because if a child has physical needs, they may be in a wheelchair, perhaps can't walk. People see those things long before they see the fact that the child can't see clearly or hear clearly, or can't see it all or hear it all, because they often get caught up in those other areas, and we care about all those areas, but our whole goal in life with children who are deaf blind is to teach them to communicate. So all those other things that are there, the physical the perceived mental challenges, cognitive needs that all sort of fades away when you just are thinking, how am I going to help this individual to communicate? And now we have lots and lots of strategies and methods, techniques to help them communicate. And now really turning into the technology. The technology, really, in the beginning, it was more tactile our hands, it was real objects. Still, is that very important, but adding that whole area of technology with things like NOVA Chat, the little communicators, all those things, there's so many adaptations that can help now with that area of not being able to see clearly or hear clearly, and we have so many more children who appeared not to be able to communicate. Now can communicate because we have all these success stories to show that if you just believe it's really up to us to figure out how to help that child communicate, not just be a receiver, but be an expressive communicator.

S Speaker 1 24:31

So in terms of deaf blindness, how important is something like early intervention?

D Dr. Linda Mamer 24:37

Hugely important. Couple things that have changed, because often when a child is born and has additional needs, not too long ago, people wouldn't have really picked up on the vision or the hearing or the combination of the vision and hearing losses. Now, fortunately, with universal Hearing Screening. Seeing people are much more aware of things. You get into the system right away if a baby is born and has other the sensory needs as well as other physical or cognitive needs. So that's huge, because then you can start right away knowing the child can't see or hear clearly, or can't see or hear at all, and then you immediately start to figure out, okay, how can I help that? And we do have early childhood educators trained in deaf blindness, who go right into the homes to help the families learn from the very beginning that this child can become a communicator. As you can imagine, COVID was awful for that, but we pivoted and did a lot on Zoom to help the families. Know, here's how you can move forward with this very complex situation, but with that idea that you can help that child communicate. So we learn about their vision, we learn about the hearing. Perhaps glasses will help. Often we don't know when they're that young, and maybe can't participate in a lot of assessments. But for hearing aids, now, that's been fantastic. So a lot of things kick in, into place if you're in like a country like ours, province like ours, and that part is is very good, because then parents understand more about their child from the beginning. The other area that's huge in the beginning, many of our children now have genetics done shortly after birth, so right away they will know, as much as that news might be difficult, at least they're not searching, spending their time searching for what is it? What caused it? They they almost, they can know almost right away. And as scary as that is, it's often very helpful, because the parents have more energy to explore. What do we need to do to help our child? And the ministry of education and child care and children and families help, they pay for our early intervention. Help our people who work in early intervention for deaf blindness, to travel to wherever the kids are in British Columbia, to go into the homes, going to the preschools, going to the daycares, to help people really understand how to communicate with this child at the same time taking into account their physical and other needs. So it's huge. Early Intervention could not be stressed more. We could use a lot more help. We could use a lot more money. But as you can imagine, the numbers in deaf blindness are not high, and then that people are early intervention. People stay with the children until they get up into preschool and then kindergarten, and then once they're in school, there's a lot of service available for children who are deaf, blind. Again, our ministry of education and child care put a lot of money into helping the schools have the resources. Again, you can always use more money, but having the resources to help those children in in the educational setting so they're actually helped to see that that child is a learner, not just someone who's there to be entertained.

Speaker 1 28:46

So you've, you've kind of already answered this, but, but let's, let's dive a little bit deeper into it. So you know, given you know your advocacy for for Intervener services, and your the work that you do as a teacher the visually impaired. What are some of the challenges that we're still finding in the system? Where are we sort of falling short in terms of being able to provide all of the services that we really need to do?

Dr. Linda Mamer 29:17

That's a great question. And you may have read the news this week about how the intervener services contract that was given to the CNIB for British Columbia was ending, was to end in March, and some of our very strong, well spoken adults with deaf blindness started advocating, and it got on television, on the news, and they basically said how much an intervener means to them. They can have a life. They can go in the community. They can go shopping. They're not dependent on family members. They can go for a hike. Very impassioned. People were pleading, really, to get more funding for Intervener services, because we have it when they're in school, and there is monies for children to have intervenors during the school breaks, and then as adults, you know, we have to carry on what we've started in school, because we've, we've, we've connected with them enough that they're communicators, going to school, university, college, having jobs, having families. So after the this impassioned PR advertising, I guess you could say on TV happened. The government said that they were now going to look at it again, which is very good, because there's a discrepancy across Canada with how much money is put into intervener services for adults, and in Ontario, it's based on hours per week. There's more hours per week available for adults who are deaf, blind and here in BC, and that's really not fair. So that's all being looked at now from a wider scope, which is very needed and very timely, because, you know, everyone has rights to communicate. So the funding is one thing. The other thing is finding trained people to provide these services. You know, we've had cutbacks in courses for people who want to learn sign language, to have trained interpreters. There's always a need for more people to be in the field. It's a very small field, as you can imagine. It's a fantastic field. Many people who go in the field never leave it because it's just such a wonderful field, a very enriching one, a very positive one. When you're all working together to help each other, it's it's really quite remarkable. One of the things we we did do with the Children's Low Vision Project is we've always seen kids who were low vision and quite capable of taking part in all the assessments. So one of the reasons I was brought on was because we were starting to see some children who are deaf, blind, again, could have some hearing and some vision. People didn't have enough information about their level of vision and their level of hearing as much as the ophthalmologists and audiologists had tried. So we decided to start looking at some of these individuals who were now becoming a little bit more proficient in their communication. And we felt if we trained these individuals to take the actual tests, we would get much more information about their vision if they came to the children's vision clinic. And in fact, one of the people who came, he's just graduating now, he came when he was about, want to say he was about 11 or 12, so we started a year long program training him to take the actual assessments. And it worked out amazingly well. And he had his Intervener there, his family, he had we had a interpreter there as well. The people at our clinic were all prepared for him. He has had a hearing aids and microphone, but the information that the optometrist and ophthalmologist in particular were able to to to to see in terms of what kind of vision he had color vision, everything. It was just absolutely amazing to see how much we could understand his vision, if people could take the time to train individuals like that to actually be part of the assessment procedure. And that has really started to change with a lot of the individuals where the assessments are maybe sort of depending a little too much on straight communication. There's lots of other ways to test the individual can't communicate to the standard tests. It just takes time. But both the rewards have been fantastic in terms of really understanding what's the best way to educate the child now that we understand their vision. And the same is true with hearing. Some of the hearing aids are exceptional now. I mean, we've had students who have been able to hear so much more clearly. Is just because the technology change, and it's really been amazing to watch the technology and the genetics as we learn more and more about that we know so much more on how things might help the individual learn to community. And then be educated. So it's a very exciting time for that. But again, we always need more trained people and more money, because, in all fairness, you can't sort of turn off your vision and hearing when you don't have someone there. We don't give someone a wheelchair and ask them just to use it for six hours a day. Oh, we have to take a back now. So you know, you think about someone who has provision and poor hearing well, they are in the world and need someone to communicate with them, and that's what an intervener does, and to have round the clock interveners and people who are well trained, it just seems fair, just seems right.

S

Speaker 1 35:43

So I'm kind of curious to hear, how involved does the family get in intervener services? Is there training involved with, say, a parent, so that they can maybe step in when an intervener isn't available, or siblings, or anything like that? How involved is the family?

D

Dr. Linda Mamer 36:00

Well, we encourage the family to be involved as possible. Because, in essence, the mother and the father the siblings, are the first interveners, really, in an informal way, I'm going to say, in that child's life. So because we're able to be in there so shortly after birth, we're already helping the family learn how to communicate with the individual, how to give them something to hold, tell them what's happening next because of what they're holding, prepare them when you're going to change the diaper by having them perhaps feel a dry diaper. All these cues and objects and gestures that we use to help a child anticipate what's going to happen and eventually add formal language to that. So we really, really encourage the family to be as involved as they can, and often then the home. That's why we have home visits in the birth to five time, because everything is done there in the child's home with the child's siblings and with the child's equipment and the reality of what they live in, we help the families learn how to interact with the child. And then when the child goes to school, the parents are a huge part of the team, the school team and the Canadian DeafBlind Association, the BC chapter, gets special funding from the Ministry of Children and Family to provide funds for interveners to work in the home during winter break, spring break And in in the summer, and so the parents are really the ones who are in charge of that and help to train that person to work with their child in the summer. So that's that's been great to be able to to offer that, but everyone around the child needs to be able to communicate with them. It can't just be this special person. Oh, we'll wait till that person comes in, and they can do that. So we build calendars that the family uses to help the child know, to help them understand, you know, you give them the their shoes when they're about to put them on, so that the child is anticipating you're wanting to take the place of what a typically developing child with typical vision would just see, oh, Mom's getting your coat on. Oh, she's getting the car keys. How do we make that a reality for someone who can't see or hear clearly, or see or hear it all right? So we're always building everyone's skill set. It can take a while. It can take a while to believe it's going to work, but we know it's going to work, and we know that the child can become a communicator. And then, as we talked before about the aha moments, once people start seeing one or two of the aha moments. Then it's like, okay, we get this now. And people just learn siblings. They learn that how to help the individual know what's going on. I know what I was going to tell you. The the onset of COVID was frightening for many reasons, but in particular, what were we going to do with children who are Deafblind? Couldn't go in the home. You couldn't do that well, I have to tell you, we decided that we didn't know what we were doing. We were like in the very early stages of just learning about deaf blindness, but we thought we have to do something. So we just started. And I, I have to tell you, we had so many fantastic things happen because of COVID that we actually presented at an international conference on the silver lining of not of COVID, but of remote teaching, right? And because you. Asked about the family. That's what triggered my mind to say that that we had interveners who would work with the student in the school pre COVID, the one in particular I saw, and just a natural intervener. He decided that they had been cooking, cooking a lot at school his, he and his student making, you know, like, things in a bowl with, like, flour and that sort of thing. So he and and mom and decided, and this was just soon as I saw it, I thought, oh my gosh, this is going to work. So the intervener was at his house. He had all the ingredients. The mom and the child at their house, they had all the ingredients. And the intervener started making, I'm going to say, like, like a pancake mix or cookie mix or something. And mom was doing the very same, and they brought a big screen in right in front of this student, who had never really been interested in screens. We tried iPads Not, not really a thing, but they started, and because this intervener and this student had a bond, which is what we really start with in the in the field of deaf blindness, the student started looking at the TV when he recognized that was his intervener. And as soon as I saw that, I thought, Oh my gosh. So they made this whole recipe intervene at his house, mom and child that house. And then that's when I thought, Okay, this is actually going to work for a couple of reasons. One, I'm just going to tell you that this student who never really watched TV, when mom turned the TV off, and of course, the interveners gone, her her son actually crawled to the screen and touched it, thinking maybe he could touch his intervener. Oh my gosh. It just was absolutely amazing. And the other silver lining that was way beyond anything we thought, because many of these kids were at home a lot longer than the typical children who were returning to school, the families became completely enmeshed in the education and development and communication of the child because they were really their interveners now, 24 hours a day, it wasn't like they were going off to school to learn everything. So the parents started having cues at the house. They started learning some simple signs, and the intervener could do it all virtually and show the parents and the siblings how to interact with the child. It sounds strange, because you think they would sort of know, but until you're actually in that situation, it's easy to think, Oh, well, he's going to go to school and learn that. You know, we just do this here at home, but the uptake of families really embracing the specific needs of the child, asking questions, what's a sign for this? What's a good cue for that? It literally exploded. It was far and beyond what. Well, we couldn't have even predicted that. And as I said, when we presented all these areas, we just kept coming up with more and more areas on how being in that very strange environment, ended up helping our students who are deaf, blind, still was our goal to get the children back into physical school and to have a one to one all day, because you couldn't be on the screen for hours and hours, but it increased how many people Were now comfortable communicating with that child, whether they were at home, parents could help. Maybe their parents, the grandparents, know how to interact with the child, because now the parents were doing it 24/7, when there was no school to go to, right? So it never really crossed our minds that it would be a way to save money, it was another way to offer more training, education and all with the goal of helping the child become a bigger communicator. It was fascinating to see the siblings, because we started having zooms now with groups, and we still do to this day. So we send out craft supplies. The child comes on with a parent, or their intervener who comes into the home during the breaks, or a sibling who then works with their brother, sister, who's deaf blind, to produce the craft and the siblings. Now getting to know each other, because they can relate to each other now, so it's opened up this whole new world of another way to help communicate. But again, we prefer in person, face to face, but some of my students still don't come into physical school because of their fragile medical conditions, right? So they have the nurses with them at home. So we're training the nurses to do a lot of the in the moment. You know, here's how you hold the book, here's how you position the iPad, that sort of thing. So the whole idea of remote was not great for a lot of kids. We We understand that, but to think it was mind blowing how great it was for kids who who couldn't see or hear clearly, just was way beyond anything we could we could ever have even not just thought about but, but and to hope for. Yeah, it was really, it was really life changing.

Speaker 1 46:10

Well, getting that family involvement can be really, really integral. You know, when, exactly when you get the the siblings engaged and involved and working with them, and, you know, networking with other siblings of other kids who may be deaf blind, you're building communities and a support network there that previously, like you said, they wouldn't have existed.

D Dr. Linda Mamer 46:34

No, and it sort of made everything seem more similar to some of the siblings you know, and the siblings would see, we all, you know, we're interacting with the individuals, their their brother, sister. We're saying hi to them and showing them things. And the the siblings became, became way more comfortable in many situations, having, a sibling, a brother, sister, who's who's that, I'm going to say complex.

R Ryan Fleury 47:11

Let's take a few minutes and just talk about the how technology has empowered the community. You know, Linda, I've heard you speak on other shows about using FM transmitters, and what a big breakthrough text messaging was. And, you know, here we are now talking about zoom right like these, these great big empowering moments for many of us, not just, you know, the deaf and hard of hearing, but the blindness community and just social interaction. So where do we stand now with technology? Are apps the go to? Is it still? Are we looking at AI and the power it may have? Where are we at with that?

D Dr. Linda Mamer 47:53

Well, it's such a it's such a fascinating area, and in the area of deaf blindness, recognizing that touch is everything when you're when you're your vision and hearing don't work well, or don't work at all. And remember, the combination of the vision loss and hearing loss, the levels of it is what defines the term deaf, blind. So it isn't someone who has, like, a little bit of a hearing loss, if that makes sense, a little bit of vision loss. It's the severity of the vision or the hearing is enough that the other sense cannot compensate for it. So it's pretty defined who is has the label of of Deafblind. So they still need touch, lots of touch, touch, touch. They need to have real objects. They need to figure out what this thing is that's coming at me. That's a spoon. They need to do all that physical exploration, even when they may not be too physically competent in terms of having a lot of complexity. So we always have to go back to the real objects. You know, people assumed when iPads came along, you could just show a picture of a cup to a child and they would immediately know what it was. We don't know what it wasn't. You don't know what it is until you've explored it in a 3d situation over and over and over again and and to build up the idea of consistency and routine and the calendar system, what day is it? Today is a school day. Today is not a school day. We're always going to have that, I'm going to say the physicality of touch, because that's what lays the foundations for all concept development. But as the child starts to be able to make sense that this is a cup, this is how I get my juice, and we start pairing it with what would lead to a photo of a cup. And if you see that the child. World can get that and that they can see that the picture is actually a picture of the cup. Because, again, just because you can see a ve cup doesn't mean your vision allows you to see a photo as clearly, in some cases, depending on the eye condition. So we have to check all that out. But what we want to do is have many ways of representing cup. So we have the cup, we have the sign for cup. We can finger spell cup or saying cup. We're gesturing with the cup. We have a photo of cup. We have the print of cup. We have the Braille of cup, whatever. And we have all of that way, ways to to give that input to the child so that they're not confused. So then, when we started to move on, for a long time, we believe that photos were, were too, I'm just going to say too visually complex for for kids to really make that leap. That's not a cognitive thing. It was. It's a visual thing. However, when the iPads came along and the clarity of the pictures, we were blown away with how fast kids could recognize in particular people's faces on the iPad. You know that the teacher who was coming in, their friend, the intervener, was going to work with them. We would have the person and the picture on the iPad, and you could see the kids starting to make sense of that. So that just opened up their whole world. So we have lots and lots of apps, we have calendars, we have books on iPads, we have timers, all these sort of things. And now the whole area of what used to be called cortical visual impairment, then cerebral visual impairment, and now it's brain based visual impairment. There's a whole area of what we call CVI cerebral visual impairment, this whole area of apps that are completely set up to be a able to be easily seen by someone who has the cortical the cerebral issues with vision. And so we're having a lot more stories that are more easily seen by by people who have CVI. And we're also matching more what the iPads offer. You know, all the accessibilities that were there from the beginning built in an Apple are just mind boggling in terms of color, contrast, size, all that sort of thing. We can do so much with that. And then we can see, is it feasible for the child to learn that way? And in most cases, it is. We still have the 3d version. Often we go back to a 3d version of something, the real thing before, if we're offering the child something new, and then we transition it to a 2d situation. We rarely go right to the 2d situation because you want to, you want to make sure that the child really understands the concept. But those things are happening quite rapidly, and now with screens, watches that sort of thing. If a child, I have a student right now who's in grade one, she has a label, deaf, blind. Her near vision is really, really good. Her distance vision is a real challenge. So she can actually look at her dad's Apple, watch and pick which apps she wants to look at those tiny little dots. So again, we have to read it as it is. Does she really understand that's what it is, is she learning the just the routine of where it is. We can do all those things to make sure she's really able to trust her vision. But now, with some of the new, what we call AAC devices, augmentative communication devices that they now have, like little buttons, like on an iPad where you can touch them. And in the not too distant past, they would say, you know, book or milk or something the latest ones. Now, when you actually touch a button, it actually makes the image grow. Could be three or four times its size. So a child who has a low vision, you may not be sure they know what the button is, but when they touch it and it gets bigger, then you can sign it, and it would have the name there. And then you're sure that they can see it, and that's a whole new level of really matching it, these AAC devices that were really just for kids who could hear and maybe have some vision, now for kids who have vision and hearing loss, we're compensating for both. Those things so there's clear sound, and then these little images can become as big as you you need for them to be able to really use their vision. Oh, well, that's what I want. And that's very, very new NOVAChat is the one that my student is just learning now, and we're all learning about it, because in the beginning, these devices were okay if you had typical hearing, but they were never a match for our students, because the visuals were so tiny, because you wanted to get so many buttons on a page right now, now that they grow, then they go back to size. You can have more on a page. So the fluidness of communication is going to come very quickly now, wow, cool. It's really I didn't I they talked about it until I actually saw it. I couldn't even comprehend what they were saying. And some you can double tap. So if the child taps it and needs an a second look at it, it comes back. You know, it's like everything. You think, oh, you know, if only we had the device do this, there's a way to make it happen now, you know, excuse me, and then, like, the sky's the limit in just that one piece of technology. Now, again, that wouldn't become their only way to communicate, because we're we're still learning signs and gestures and the real object and fingerspelling, and the kids in the class are all learning sign language every every week they have a little video lesson on it. So there's all these things that are now sort of our go tos for children who have vision and hearing challenges. But I have to get back to the text, oh gosh. It had to be about I want to see 2010 ish around then, and I was at a conference of on deafness, and it was just downtown Vancouver, and it was just around the time when the blackberries Were coming out with techs. So if it wasn't 2010 it was, it was when that happened, and I stood there in the in the foyer, just watching all these people who are deaf communicating with each other. It was they've never had that opportunity of such rapid and then I could text my my friends who are deaf blind, six, seven times a day. They didn't have to go get someone to read it to them and then sign it to them. It was the immediacy of the BlackBerry and text was, there's not even a word for it - a game changer. Really doesn't even it was. They were instantly communicating with people around the world and and without anyone else. Yeah, yeah. It was that was just so exciting to see and, and you could see their excitement about, oh my gosh, you know,

R

Rob Mineault 58:07

And it's, it's amazing to think that that's only 15 years ago.

D

Dr. Linda Mamer 58:10

I know I can remember this as I'm standing there right now just watching it all. I thought, This is it. These people now have their independence.

S

Steve Barclay 58:19

It's fantastic you, you brought us back to NOVA Chat, because that actually brings us back to Aroga, where Rob, Ryan and I used to used to work, and that's a product developed by Saltillo, who we used to represent when we were at Aroga, which was a spin off from practical ramen company, who we used to represent when we were at Aroga. So I'm thinking, Ryan, we need to reach out to Arlene. She's the Western rep for Saltillo and PRC, so I think we should, we should reach out and see what's going on with those guys.

S

Speaker 1 58:59

Yeah, yeah. It's actually opens up, you know, a really interesting topic too, which is, you know, sort of the intersectionality of Assistive Technology through the evolution of technology. Because really, you know, we could see assistive technologies being developed that is for a wide range of disabilities, instead of, hey, this is a low vision device. And this is, this is the only thing it works for. This is a blindness device. You know, we may, we may see more devices that actually could help with people who have multiple disabilities, which are, which are a lot of people out there. So it's exciting time.

D

Dr. Linda Mamer 59:39

It's like what Steve has in the store when he opened up that whole area with all the devices to help people who are dealing with aging problems. You know, we used to think of things like vibrators and flashing timers as really for people who were deaf. And yet, there's a whole population of you. Other people who need that, and there, it's all accessible. It's in many of them have large print on the screens. And just to see how many things, Steve keeps adding to that array at such a lovely rate, like it gives us great comfort for when we're going to need stuff. And really it is the intersectionality of, we're all going to need this. We're all going to need tactile markers on stairs and all these things. And it's, it's, it's very, very exciting and and to, just to tell you my I was a very early adopter of the iPad. And I'll tell you what story I heard, and this was probably the first time I thought, oh my gosh, this is going to work like the like the BlackBerry at the at the conference, someone sent me a tape of someone was interviewed on CBC, and this person was a farmer, and the farmer was totally blind. I think they lived in Kingston, and he had, I want to even say it could have been an iPod. It was very early on, but he was a pumpkin farmer, and the one thing he could never do was tell you the color of the pumpkins. He had to have someone with him. So he'd get his wife out and say, What color is this? What color is that? And when he could figure out how to identify color with one of the Apple devices, and he said, I can now be independent in my job, I just stopped and thought, This Changes Everything, and it and it's it's light, it's cheap, it's handy, but to that man, that meant everything. And it was right there, yeah, the color of his pumpkins, I will never forget that moment. Just just the possibilities.

Speaker 1 1:02:03

That's why, you know, AI is so exciting. Because, you know, literally, we're we're on the steps of another huge revolution, right, where someone can take a picture of a room and it will literally just describe everything in that room through AI. So, yeah, I feel like we're on it. We're on the cusp of a few different types of revolutions that are really going to affect the assistive technology field. So it's a pretty exciting time to be talking about it.

Dr. Linda Mamer 1:02:29

It's very exciting. It's hard now. It's almost overwhelming to try to keep up, not just with AI but but once I figured out I I myself don't have to know everything about like, every app. You know when they started multiplying so quickly, but I now know how to find one. Yeah, yeah. I know you can describe to me what you're looking for, and we can go look for something. I don't have to know that app in advance, right? Yeah, that was very freeing for me.

Rob Mineault 1:03:00

Yeah, well, and they're popping up, like daily. So, you know, we just had, like, last week, 10 days ago, we had this DeepSeek thing happen. It's completely shaken everything up. So, yeah, it's, it's, it's an exciting, definitely an exciting time.

Dr. Linda Mamer 1:03:14

It is. But, you know, everyone needs a good tech person in their life. And Steve has always been my go to guy, because, one, he knows, but two, no question is too stupid, or he's so good at explaining it, and not just because he's here, because I send a lot of people to Steve, because of that very comfortable, easy approach. Oh, and I'll tell you one last story. This was years ago. We were down at his store with one of my newer students when I said I got into teaching students who are visually impaired, because I want to learn about the technology. And we brought our student down. I think he was maybe like grade seven, and he was sitting in front of one of the CCTVs that we were thinking about going through our technology, special education technology, BC, set BC. So he's sitting there. I'm standing behind, talking to his mom, and Steve was just sort of circulating, because Steve really believes you have to sit at this thing long enough so you feel comfortable with it. So we were just letting my student do it, and all of a sudden, talk about aha moments, and I'm talking to the mom and and I heard my student go Oh. And we looked at him. He had figured out how to turn the camera on his eyes so he could see his own nystagmus on the screen, and now it sounds simple. Now we have all our kids do that. That was the first time, and he'd figured it out himself, and the mom and I just stood there and started to cry. It was just so amazing what technology opened up.

S Steve Barclay 1:05:03

I did, I did that with a bunch of kids at the CLVP clinic. Bunch of kids, yeah, because most of them have never seen their nystagmus. They don't, they don't know what it looks like, or they don't even think, like, how, and I don't know.

D Dr. Linda Mamer 1:05:19

Because, you know, we would probably said, look in a mirror, but when he put that camera there and then on the screen, as we could just see it, we're standing right there. Oh, it was such a moment for everyone. It was emotional, it was scary, it was, it was just such a moment of how curious, but what technology just opens up when you really when you least expect it. And again, back to Steve, just really believing if it takes you two hours to sit in front of a machine so you can, you know, check everything out and be comfortable and no pressure, and ask all your questions, then that's what it takes. And it's one of Steve's met, one of Steve's many gifts.

S Steve Barclay 1:06:11

Thank you.

D Dr. Linda Mamer 1:06:12

It's true.

R Rob Mineault 1:06:14

His other one is dad jokes.

S Steve Barclay 1:06:17

Just thinking that just, I'm just feeling real humble right about now?

Rob Mineault 1:06:20

Well, Dr Mamer, I got about three questions into my list of questions, so you're gonna have to come back because there's so much still left to talk to you about. Please come back soon and and we'll do this again.

Steve Barclay 1:06:40

We'll do it with wine, so she's even more expensive.

Dr. Linda Mamer 1:06:46

And Steve's a very good host as well. We won't even get into that.

Rob Mineault 1:06:49

Yeah, that's a whole different podcast. Is there anything, anything you want to plug, any any organization, anything you you want to put out there into the into the world.

Dr. Linda Mamer 1:07:04

Well, our Canadian DeafBlind Association, BC chapter, does a great job supporting all the families in our province as part of a national organization. The Canadian deaf blind Association in June is national, or really international, deaf blind Awareness Month, and we have chosen to do yarnbombing, where people knit stuff, and then we wrap them around trees, fences, sheep, and Make awareness of how we're all sort of meshing together around the world, and people share these pictures of yarn bombing, and it's a very tactile thing. So in June, you may see things around or you may hear of yarnbombing, and what it means. It's a worldwide approach to build awareness for Deafblindness, and it's really picking up steam.

Steve Barclay 1:08:03

Come June, we'll expect a good yarn. Two dad jokes, one show.

Speaker 1 1:08:13

I know right, our numbers aren't gonna be able to handle it. Servers will go down all around the world if they download. Dr Mamer, thank you again for coming on. We really appreciate it. And yeah, like I said, Come back anytime.

Dr. Linda Mamer 1:08:34

Thank you. It's been wonderful, and thank you. And Lis, nice to meet you. Thank you for all you do spreading the word. I can't believe you're into the hundreds of podcasts. I think it's in the 400 to 500 range now. Thank you for all that you do.

R Rob Mineault 1:08:56

We do what we can.

D Dr. Linda Mamer 1:08:59

Nice to meet you too. Lis,

L Lis Malone 1:09:02

Bye, bye.

S Speaker 1 1:09:03

Man, I tell you, I could have, like, talked to her for another hour. Well,

S Steve Barclay 1:09:09

She would have talked to you for another hour.

L Lis Malone 1:09:11

I was just sitting back and listening, and it was just so fascinating.

R Rob Mineault 1:09:16

Yeah it really is. And I've got a list of, actually, other things that I would love to have her on to talk about specifically. We'll talk about the intersection of disability. it blows my mind that that their story about the NOVAChat, because I remember the NOVAChat from our Aroga days. AAC devices in general, and back in the day, there was no way that that somebody was Deafblind, was using one of those. Like, there. Is no intersectionality at all between disabilities, usually in any piece of assistive technology. So that's really exciting. This idea that you may have all of these devices that are actually can span across different disabilities, that's so cool.

S Steve Barclay 1:10:17

Yeah, I think that you know, of course, of course, these products evolved from when we knew them, you know, we've just sort of lost touch with them to, you know, with with one thing and another. But, yeah, it is great to see that they've evolved to a point where they're reaching out to other populations that that really need them.

Rob Mineault 1:10:40

All right, well, that show went long, so we better wrap up here for dinner. Ryan's getting Ryan's getting hangry. Hey, Lis,

Lis Malone 1:12:59

Hey, Rob.

Rob Mineault 1:13:11

Where can people find us?

Lis Malone 1:13:12

They can find us www.atbanter.com

Rob Mineault 1:13:14

They can send us an email if they so desire, at cowbell@atbanter.com.

Steve Barclay 1:13:44

Yeah and rumor has it that there's social medias out there. I've been, re engaging with some of these social medias. So, yeah, it's interesting. So we've got what the got, the Facebooks, we've got the Instagrams.

Rob Mineault 1:14:01

Yes, yeah, we've got picture pancakes up there.

Steve Barclay 1:14:04

Yeah, well, we got mastodon. Who owns Mastodon now?

Rob Mineault 1:14:17

Don't know that's actually it, isn't it? What's Bluesky?

R Ryan Fleury 1:14:21

BlueSky was Facebook.

S Steve Barclay 1:14:27

These ones gonna go evil too?

R Ryan Fleury 1:14:31

Absolutely.

S Speaker 1 1:14:35

Facebook is Meta, right? So anyway, that's Threads, but not BlueSky.

S Steve Barclay 1:14:39

blue sky was going to be old, Sorry, Steve, blue sky was going to be the ex guy from Twitter, his new platform, right? Right, but we already have master, so we don't need a Twitter. That's right, yes, and other Twitters right? And let's just go back to calling each other on the phone. Let's forget, yeah, how about that? That'd be a good idea. Yeah, let's let's just do that. That's why we need party lines.

R Rob Mineault 1:15:14

Yeah, remember the party lines? Or the 1-800 numbers? Oh wait, nevermind...

L Lis Malone 1:15:30

S Speaker 1 1:16:12

Yeah, yeah, that's right. Visit www.canasstech.com, for all your Assistive Technology needs. That's going to do it for us this week. Big Thanks, of course, to Dr Linda Mamer for joining us, and we will see everybody next week.

S Steve Barclay 1:16:42

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