PODCAST Episode 462

Sun, Jul 19, 2026 10:36AM 1:08:33

SUMMARY KEYWORDS

Assistive technology, low vision, vision loss, Stargardt's disease, video magnification, rehabilitation services, bear spray, grief process, smart glasses, macular degeneration, low vision conferences, counseling, peer support, technology advancements, memoir.

SPEAKERS

Lis Malone, Speaker 1, Tom Perski, Steve Barclay, Rob Mineault

---

R **Rob Mineault** 00:16
Hey, and welcome to another episode of AT Banter.

S **Steve Barclay** 00:22
Banter banter. Insert cowbell here.

R **Rob Mineault** 00:26
Yeah, that's wow. That was a pretty. That was a sad cowbell.

L **Lis Malone** 00:30
Hey, give me a break. I tried. Come on.

R **Rob Mineault** 00:32
You did.

S Steve Barclay 00:34
A for effort.

L Lis Malone 00:36
Can I have a redo?

R Rob Mineault 00:38
Yeah. Okay. Sure. Sure. Yeah. Let's. You want me to set you up, or do you gonna do it? Here, I will set you up. Here we go. Or around Steve, you set her up. You you do the banter, banter.

S Steve Barclay 00:50
Okay. All right. You ready?

L Lis Malone 00:51
Yeah.

S Steve Barclay 00:53
Banter, banter. Oh, soul strike there. Yeah.

R Rob Mineault 00:57
That was better. Yeah, that was hard. I felt the vibrations here.

L Lis Malone 01:02
You know what? See, the first one was was heart. This that one had soul. There you go.

R Rob Mineault 01:07

That's right. Perfect. 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's Rob Mineault, and joining me today, Mr. Steve Barclay.

S Steve Barclay 01:25

I'm back, baby.

R Rob Mineault 01:27

And Miss Lis Malone.

L Lis Malone 01:31

Hey, I never left.

R Rob Mineault 01:34

You're always here. Yeah. How the heck are you, folks?

L Lis Malone 01:39

Aside from being the cat that you fed once and won't leave, great.

R Rob Mineault 01:44

It's true. I have a few of those in my life. Ah, yeah. Well, and what about you, Steve? You're you're fresh back from vacation now. You were camping. How'd that go?

S Steve Barclay 01:56

Went well. We we only got rained on a little, so that's an improvement over years past. And yeah, we had the whole the whole family out, so there were seven of us out in Golden Ears Provincial Park for a week, fending fending for ourselves in the wilds.

R Rob Mineault 02:13

Nice, yeah. I guess it's it's been a bit of a cooler July here in Vancouver in the Lower Mainland. So, what was it like? Were you guys chilly?

S Steve Barclay 02:24

No, not chilly. I mean, it was nice and cool at night, and it was warm during the day. You know, we had a couple of cool days when it was overcast, but no, it was it was perfect, perfect camping weather.

R Rob Mineault 02:35

Sounds ideal.

S Steve Barclay 02:36

Yeah, and kind of funny story about that. We up in the Provincial Park. There were bear warnings all over the place saying, "Oh, you know, make sure your food's put away because you know there was a bear spotted here. And we've we've always been very bear conscious when we've been out camping, so we weren't worried about it. But we went through the entire camp. The only wildlife we saw when we were driving into town, as soon as we got out of the park, we saw deer, but nothing in the park. The only wildlife we saw in the park were like squirrels. And then driving home, Jackie goes to drop her brother off at his house. There's four bears out beside his house. And then we we went to drop off the van that we rented. And driving home, we go past another bear walking into the parkade of one of our neighbors' places. So there's more wildlife in Burnaby than in a Provincial Park, apparently.

R Rob Mineault 03:32

Yeah, I've heard that actually. I was talking to somebody the other day that was talking about like a bear had wandered into the complex, the townhouse complex that they're at. So yeah, it seems to be happening more and more these days.

S Steve Barclay 03:45

Yeah, yeah.

R Rob Mineault 03:46

So lucky here in New West, all we get are raccoons. There's a lot of raccoons.

L Lis Malone 03:50

Well, I I feel like now anytime we turn on the TV here, it's like animals are just deciding to kick ass and take names. All I'm hearing is like alligator ate this person, bit this one arm, shark attacks, bear attacks. I mean, it's it. I I I can't tell if it's that animal attacks are on the rise, or we just have so much more capabilities of having things documented because of phones and security cameras. But it just I I'm I'm like so afraid to to be out in nature.

S Steve Barclay 04:24

Yeah, I I think it's the latter. I think it's just coverage.

L Lis Malone 04:27

Yeah, it's still scaring the crap out of me.

R Rob Mineault 04:31

Yeah, no doubt. Because what do you like? What do you do? You know, you're walking along the street and you just run into a bear? Like all my bear survival instincts that I that I developed as a kid growing up in in the northern interior have all gone now. I have no idea what to do if faced with a bear, like because I know one one you're supposed to run, one you're not. You play dead. You find a tree. Like then where are you going to find a tree in the city?

L Lis Malone 04:56

It's two words: bear spray. Learn it, live it, carry it.

S Steve Barclay 05:05

Well, you know how they they they tell you you should deal with the different types of bears, right? Like black bears, they they're they're smaller. You can tell when they're around because their scat has little seeds and small bones in it. You know, not not nothing too big, and you can carry bear spray and and and wear a bell. If you're if you're in brown bear territory, the you know the the scat's a little larger, got larger materials in it. And again, you can use bear spray and wear a bell. And if you're in grizzly territory, you can tell the scat because it smells like pepper and and has bells in it.

L Lis Malone 05:48

Well, you know, I don't I don't normally look for that while I'm being mauled, but I'm gonna I'm gonna keep that in mind. That's really good advice, Steve.

R Rob Mineault 05:57

You know, you never know what you're gonna learn when you tune into AT Banter.

S Steve Barclay 06:01

Indeed, yeah. There you go. There you go.

R Rob Mineault 06:04

All right. Well, enough of that, because I am excited to get to today's guest. So, Steve, could you do the honors, and could you tell me just what the heck we're doing today?

S Steve Barclay 06:18

Yes, indeed. Our guest today has spent decades turning his own experience with vision loss into a mission to help others. At 19 years old, he was diagnosed with Stargardt's disease and lost his central vision-a diagnosis that forced him to drop out of college and give up driving. But he didn't stop there. With the help of video magnification technology, he went back. He finished his degree and built a career that's made him one of the most recognized names in low vision services. For years, he read he led rehabilitation services at the Chicago Lighthouse, running their assistive technology center and tools for living store, helping 1000s of clients find the right tools to reach their maximum potential. He also was who introduced me to IrisVision, one of the first virtual reality-based headset magnification systems. Please welcome a true pioneer in low vision technology and advocacy, Tom Perski.

T Tom Perski 07:09

Thank you so much, Steve. Appreciate it, and good to be with you, Rob and Lis. It's I've been looking forward to this for quite a while.

R Rob Mineault 07:18

Yeah. Well, listen, I we are really excited too, because you know we're we're of course big assistive technology geeks here on the show, and we you know Steve and I have worked in the in the industry for a long time, and so it's always sort of a a special pleasure to to be able to to talk to somebody who's been in the industry probably longer than than either of us. But maybe maybe where we can start is telling the audience a little bit about your own personal vision journey and and how sort of that all played out.

T Tom Perski 07:50

Right, as Steve mentioned, I was diagnosed at 19 playing American Legion baseball, where the ball went up in the air, and I was playing center field, and I was I saw it come off the bat, and it went up in the air and went into some black hole somewhere. I missed the ball and was totally embarrassed, you know, and came in. I told my coach I wasn't seeing the ball correctly, and went. Mom and Dad wore glasses, so it was to the family eye doctor, and he saw something in the back of my eye that he said needs further investigation. And I was fortunate enough to be sent to the University of Chicago, is where I'm from originally, and one of the top doctors in inherited retinal diseases, Doctor Alex Krill, he knew what it was right away. He was the kind of the world expert and wrote books for ophthalmologists on the subject and told me that you know my vision at that time was like 20/40 so I was you know doing everything pretty much normally, but that was the cause of my first inkling that something was wrong. And he said, "It's going to get worse. You're going to lose the center part of your vision, become what they call legally blind, which I had no idea. And I think I shut down at that point and decided not to listen, and my family had no, you know, no background, and we all thought, you know, I'm just gonna go along and do the best I can, but he was right. This over the next year, I had lost enough vision to be kind of in the 2060 rank, and so the you know that starts to be problems in reading. And I was in college, and also an art major. So I just made my paintings. My professors would tease me every time you come in with a new painting, it's larger than the one you had last semester, and it was just my way of trying to cope and really not tell people too much. I was too caught off guard. I didn't want to face it myself, let alone you know talk to others about it. So that that was the beginning of my journey, and by the by my junior year, I could no longer read, and I did drop out of school. And then I, you know, the the uncertainty. I think of what where do you go from here? What kind of job can I do? All of those feelings of moving back home and being depressed and and more angry too. I think to sort of cover over those deeper feelings. I'd rather be angry than super sad, you know.

R Rob Mineault 10:54

Right.

T Tom Perski 10:55

And and that's kind of how I faced it for quite a while. So it took it took several years, years and years actually of coping and figuring out through the Department of Rehabilitation. They said, "Oh, we have special tests that we can maybe help you get back to college." And in these tests, they brought me in and they said, "You know, you you've done these personality profiles, and we we have the results. And I was like, okay. And I'm thinking these guys probably don't know what they're doing. And they said, well, we see that you could really be either a psychologist or a priest. I'm like, what? What is he talking about? I'm an artist. That was their findings, but they said, no, no, no. We we're serious. We can pay for you to go back to school, and so at 26, I went back to college, and that year, okay, believe it or not, was one of the visual tech was one of the first CCTV video magnifiers. It only been out what two years, so I always tell people mine was made out of stone. Had big stone knobs on the front, you know, and the little guy would come out and chip away each letter,.

S Steve Barclay 12:24

All stylishly presented in a wood wood tone box.

T Tom Perski 12:29

Yes, and my younger colleagues who've been around not quite as long as I had said theirs was like wood siding, like you know, like the station wagon we had as a family member, but mine was definitely stone, and but it saved my it saved my life. I talk about assistive technology and what it did for me way back when to go to finish college and finish graduate school. I mean, I couldn't, I couldn't imagine where I'd be, you know, and how that turned into a way that I wanted to help others to go through the journey, their journey, as I never had the help to go through my my own.

S Steve Barclay 13:20

What what was there for? Were there any kind of services back then?

R Rob Mineault 13:25

There there was low vision services in major cities, but I was never referred to to them, and I I did receive a a thick pair of glasses, where I had to hold the book about five inches, but that went in a drawer and never came out again. And so the the services that I received was going back to school and and and buying my books and my tuition, but there was no vision services that I knew about, and I struggled for years. And besides, you know, having to bring everything to the CCTV, and of course trying to read and trying to cram for a test, and the room would start to go around, and I'd get dizzy, and I'd have to lay on the couch, and and then the room was still spinning, and I'd have to lay with my head on the floor, and hoping that the room

would stop spinning. And so, finally, by graduate school, I had met a blind student at the university who told me, "Hey, didn't you know you can get your books on tape? And I thought, no, I don't know about that. And so, we found out about it's called Recordings for the Blind at that time. And I got my first like six or seven books, and I sat in my easy chair. I thought, this is going to be great. I don't have to sit up at the. This 12-inch black and white screen anymore, and within 10 minutes, I was fast asleep. You know, and the book would keep playing, and then I'd wake up a half hour later and have to rewind the book, and the words just they wouldn't go in. You know, they were. I wanted to see the words, I was a visual artist. I wanted to see things, not hear them, and so my brain had to really do a lot of hard work to kind of reprogram itself. Really, is what it did, but it took a long, long time, and it it was hard. It was definitely hard, and the neat thing was when I did graduate and worked as a family therapist for a few years, and there was a big Ophthalmology center outside of Chicago in Wheaton, Illinois and I had a family friend who was on the board of directors for a new Low Vision Rehab center that was going to be sponsored by this large, the largest Ophthalmology center in the Midwest, and they were looking for a counselor, and so they they sort of knew who I was, but they didn't know my background, and so they asked me to come for a tour. And as I went through the the center, and it was a beautiful new place with contrasting colors and special lighting, and it was like a home that had been made especially for people with low vision, but it was actually the clinic as well. And then when I walked into the doctor's office, I saw the eye chart. I said, "Oh yeah, this looks very familiar. And the woman, Doctor Mary, her name was, and she looked at me. She goes. What do you mean? I said, Oh, you don't know. I'm legally blind. You are? Oh, that's wonderful. So, Doctor Mary, no one's ever quite said it to me that way. Well, you know what? You know what I mean. You're going to be able to relate to people who come in, and you've been through it yourself, and she didn't know. And I think she was kind of looking at me too. She just like she didn't say it, but I knew she was saying, "You really don't look blind, you know. And and that was that was pretty amazing. And in my background, while I was in college or graduate school, I did attend three years in a row the blind ACB conferences in, and it was you know there was no emphasis at all on low vision. It was not that people were all totally blind. Of course, they had all different levels of vision, but people were using canes and dogs, and and it was a world that was just so frightening to me. I didn't understand it. I thought it was kind of interesting, but I always felt in the back of my mind that low vision is, you know more the incidence of low vision is three times higher than those with totally blind, and so why isn't there a low vision conference? Why isn't there help specifically for us? And as I worked at that low vision center after several years and made contacts with all of us in in Chicago and Illinois, the Department of Rehab. I insisted that we try to have a Low Vision conference.And the very first one was in 1991, and we had 800 people that came, and we had some of the top doctors in the country at that time, who were pioneers in in their own right, and that conference became the first in the United States ever on low vision. And two years later, we had over 1000, 2 years after that, we had 1200 and 2 years after that, we had 1500 people. So it became the '90s. Became a time when, when I was recognized as somebody who was making an impact and making the low vision community, you know, a real community for the first time.

S Steve Barclay 19:33

Nice. It's hard to imagine back then because there is quite a sense of community now in the in the visually impaired and blindness community, that I think the number of that is probably just being able to connect more readily.

S Speaker 1 19:47

You think about the early '90s, and you know, baby boomers were what in their 30s or you know 40s. I mean, the the incidence of Macular Degeneration especially was not talked about. People did not know what it was, if you can imagine that. And there was there was no injections. There was you know hot cauterizing laser treatment and things like that for patients. But but really, it was not it was not very well known, and of course, when was it about 2010 when people started turning 65 at like 10,000 people a day? You know, this macular disease being like what one in five over 70 now in developing countries all around the world. So that's you know we're at a point in history where macular degeneration has never been as much as it is right now in the world, and that will probably change it as the baby boomers you know die off and goes back to another kind of a different kind of a world. But right now it's it's really amazing. So for me to watch what happened in the technology world, especially you know when all of our screens were giant television sets that weighed 35 pounds. Yeah, and you know flat screens didn't come in till what the early 2000s and and that changed everything. You know, when the only thing was a large desktop CCTV, that was the only thing in the world for several decades until the the small flat screen screens came along, and so it was fun. And when I later in my career, I worked as the Senior Vice President of the Chicago Lighthouse for the Blind, and we had a technology crew, four young guys that knew a lot more about the technical things than I did, but I brought a lot of focus groups into helping different companies, and we just had a great time. You know, I was on the committee on the they called it The Dream Team at Humanware when we made the the Prodigy software and and some of their first products, I helped immensely on products like the Explore 5. Was was me and Luis Philippe that did that. I used to call it the Explore A Five. I would tease tease them. I got involved right from the start with Rob Hilkis and was helpful in developing the first e-Sight program product, and wrote their first training manual for the company. And these are just a few samples of, for me, you know how I just and I I never charged anybody. I just wanted to be a part of making some of this technology available, and what I thought as a person who's lived with it now for over 50 years, what it's like to to help others and to like I was saying to turn my life around and we can we can do the same you know never thinking someday I'm going to have smart glasses or I'm going to be talking to Siri or you know that was just not even close to what I thought the world would be like for me.

S Steve Barclay 23:42

Yeah, that was all science fiction.

T Tom Perski 23:45

It really was. It really was.

R Rob Mineault 23:47

So, sort of speaking to that - and this is this is where your story is so fascinating because I feel like your lived experience really informs these these different parts of your career. You know, first, you know, being involved in in counseling, in in rehab services, and then you know the assistive technology part. You know, the fact that you sort of you you know you lived the experience as well must really gives you a a really unique perspective in your experience, like what what parts of that lived experience were you sort of able to bring to to the counseling when you were counseling other people who were sort of freshly diagnosed, and how important do you think that lived experience is for counselors that are sort of involved in helping people through that process?

Tom Perski 24:40

Yeah, that it's you know has been extremely close to my heart in the work that I was trained to do. Actually, Doctor Mary would she was a retired psychiatrist, so she said let's meet every Tuesday morning, and and she was guiding me. I was still in my early 30s. You know, and she met with me every Tuesday morning for eight years. I mean, the kind of training that I had was just-it was incomprehensible. Really, I was at the right place at the right time, and and so not only did she help me through it, but she helped ingrain into my thinking how people respond. What stage are they in when you sit down to show somebody a piece of technology to be able to assess? You know where are they? Are they you know in that early stage where they're just not ready? You know, and what do they need at that point? You know, they need hope. They need the fact that something is out there that will help them. But they're going to push it away as fast as they can. You know, and they might. You know, I can count a million times in my career where somebody came back six or nine months later and said, "You know, Tom, you showed me something last year, and I'm ready now. I got my checkbook. I'm ready. You know, it's like they just could. They just were at that point. You know, and the other thing I think is that we never talked about at least the doctors that I worked with and as a team was the the grief process that you're losing something very you know very near and dear to you and losing your vision, losing the ability to you know to drive your independence. It seems like you're losing, losing, losing. You know, at those first several months or years, and people don't talk about you know taking the time to grieve those losses, and that takes either counseling help with with a grief counselor, or people that myself I used to just take myself to a local park and lay in the grass and and look up at the stars and shed some tears. And I would do that quite often to try to say, I'm gonna try to let go of what I thought my life was going to be like, and try to instill in myself that life can be, you know, vision loss is difficult, but it doesn't change. It doesn't mean your life is going to be totally difficult, you know. And I think that's the message I always try to let people know and help them understand that it's okay to cry. It's okay to get, you know, get through the process as much as you can, because then you're you're going to be balanced, you know. And and when I was training my young staff on how to do a how to do a demo for CCTV, you know, I'd say slow down, go slow, pretend you have all day, because there's something going on inside of them that you don't know yet, and you're showing them what knobs do this and what what you know colors come on the screen, and you're all excited about showing them. But you know, think about what they're where they are, you know, right? And then if there's a family member sitting next to them, you know, because of my family therapy background, I could see. I call them. Are they butting in the family member? You know, trying to do everything for the person. Right. So I called them the butt inskis, and and the but inskis are always. You know, and I would have to put my hand out like a referee. Just wait. You know, so and so is going to do it on his own. You know, and then we had the I called them the Bud Outskis, where they would we would go to do a demo, and the person I'll wait in the car. I was like, no, no, no, you won't. You're going to be sitting right here because we're going to be talking about things that are going to be helpful for you to be a coach, you know, and and you're going to you know understand to be a part of this because this person really needs you, you know. So there was like all these dynamics going on around what we're trying to do to help the person see better,

R Rob Mineault 29:22

It's so interesting, and I think that a lot of people outside the industry don't really realize just how how personal assistive technology is. Just from a variety of different things. One device can help somebody in one way, but then it might help it in another. One device might work for one person; it's not going to work for somebody else, even if they have the same condition, because they're they their their the acuity might be different, or their situation that they need. For could be different, so there's so many variables when somebody sits down to try a piece of AT, whether or not that that is going to be the right piece of tech for them, including and I didn't even think of this until you were just talking, including again what's going on with them in their journey, what they're ready for and what they're not ready for.

T Tom Perski 30:21

Yeah. That it's so it's so important. And if you get it, I always say if I had a chance, and I often do several weeks before somebody comes in to say write down everything that you can no longer do or that you're trying to do, but you're really frustrated. You know, in the next two weeks, maybe you'll have 30 or 40 things on your list. You know, and a couple day, a day or so before you come and see me, I want you to take that list of 40 things and prioritize it. I want to see what your top 10 is, and that's not only helpful to me in helping them, like you were saying, like what piece of technology is going to be best, but it's helping them think through instead of just thinking, "Oh, they're going to show me something to help me see better. Right? It's it's going to help them think through before they get there, what is my top 10? You know, what is the things that are that I really want to be able to accomplish? And you know, our research for years always said that you know seven or eight things out of 10 are are very doable. You know, within a short period of time with the right technology, you know. Maybe driving's not there, but that's on everybody's list. But you know, but so many things that can be accomplished, and then helping them understand this is a process, and let's let's have some success. Certainly, let's practice everything that I show you. I want you to do 10 or 15 minutes in the morning, 10 or 15 minutes in the afternoon, and I want you to do it every day. Don't skip a day, because you and your your eyes and your brain have never done this before, and especially if you're, you know, elderly and you're maybe you're depressed or going through struggles, so there's a lot going on inside the person, and they they don't they decide, oh, I'm not going to read for the weekend, and then I'll start back on Monday, and then they forget what the buttons do, and you know all those sorts of things. So that was always my mantra. You know, two or three times a day on short periods is better, and so you're not overwhelming. You know yourself, and and then don't skip a day. You know, just go on and try to do it. And it might be just about anything that we're helping people adapt to is can that can work for people.

R Rob Mineault 33:10

I mean, it must be such a fascinating perspective too, because you know, literally going from going from a time when, like you were talking about, like CCTVs were like literally, it was like literally a boat anchor.

T Tom Perski 33:24

I know a few models that I could. I should have used this as a boat anchor.

R Rob Mineault 33:31

I'll bet. But but now you know you could you can carry it under one arm like a lot of these you know a lot of these flat screens. But I mean, but that's just form factor. But do you find that that these days more and more devices they're able to sort of roll multiple use cases into one device. It seems to me that that that's one of the things that's really improved with assistive technology, where it's no longer you need this device for this task, you need another device for another task. How do you find that part of the industry has has developed in the past few years?

T Tom Perski 34:09

Oh yeah, that's amazing. That's a really amazing thing that's happened. Is that you know, like you were mentioning, just one or two devices that can do not only you know like the smart glasses, like the Ray Bans or whatever, you know I'm working with, I'm volunteering as a low vision director in our small town, and so I see patients in their 80s as primarily that are using smart glasses, and not only can they read and and know what time it is and what the weather is, but they're asking you know what what kind of macaroni and cheese can I make, and you have a special recipe, and I mean things that we just never you know never dreamed of, and being able to translate in other languages when they travel, or to be able to read signs in French or Spanish, or I mean, just things that go way beyond somebody's 10 list, right?

S Steve Barclay 35:13

Right.

T Tom Perski 35:13

And and the smartphone, you know, people earlier in my career, I never saw anybody over 70-five with a smartphone. I just never did, you know. And now everybody has one, and so we we developed an app we call Live Read. It's a it's an it's only in iOS. And my young colleague who I've been working with, he's getting all excited about low vision. He he developed this app that just works really easily for those 85 year olds that we see. That opens the app and it reads out loud to them. So by the time they leave their first appointment, they're they're able to read their mail, you know, read their pill bottles just with their own smartphone, and and that's been really fun. And so, yeah, recently we had a really nice community event. I just over the last three years, I wrote what I felt was a memoir that I was trying to inspire people of the things that I went through, and all the stories that we talked about earlier in my 20s, and how I made it into the low vision field, and how we developed the whole low vision conferences in the 90s, and so I titled it "There's No Vision Like Low Vision" is the name of the book. I love it, and it's there's a foreword by an ophthalmologist colleague of mine, Dr. Byron Tabit. It's Initio Press, which is, I believe, in Edmonton, and these guys have been really super helpful in developing a new neat book cover and just a quality product. So I I appreciate their help, and I told them I do watch Oilers games, and when you know I grew up in Chicago when it was the original six. You know, and Saturday nights all the games were on, and so I followed the Blackhawks. You know, through their through their great times, and when Duncan Keith went to the Oilers, I decided I was going to watch them from now on. So, so that's my one of my connections to Canada as well as Humanware, and I keep in touch with those guys. And my work with e-Sight was fun.

R Rob Mineault 37:56

Okay, so let's talk about the book a little bit. So, what what sort of prompted you to write the book?

T Tom Perski 38:03

Yes, I think it really was that I knew that Macular Degeneration, you know, is affecting more and more people, and I really felt like, okay, yes, the age difference, you know, of course, is huge when having it at 20 years old, but you know, you really can't stump me when you talk about what questions that you do you have. You know, I've lived through it all, but I never really disclosed to people what is going on inside. You know, the interpersonal thoughts that I put in this book are are pretty deep, actually, but I I did that on purpose because I wanted people to know that there is hope that you you do feel that like you're going through a journey by yourself a lot, and you you you're not sure you're going to come out the other end, and all the things that that I went through. But it was certain people that I met, you know, and my very first friend Tony, who was who had low vision, it was a life changing experience, and so I talk in the book about you know having somebody that you is going through with you, and then I felt as a counselor, I was trained in group group therapy, and I said, like, there is no low vision support group in all of Chicago. And so, in 1983, as a as I was still a graduate student, I decided let's have a a low vision, and so the local CCTV guy he had been selling CCTVs probably six or eight years, and he said, "Well, I'll just send an invitation to all of the customers that I've had over." Years, I thought, okay, we rented a room, and the good thing it was a very large room at the local library because 60-five people came to the first meeting, and we sat in a circle, and we literally it was a Sunday afternoon. We literally went around the circle, and everybody told their story, and the tears were flowing and the Kleenex boxes were being passed, you know, and it was like wow the the the need you know of what I at that time was had been going through a little over 10 years, but now to to be in a room full of other people, and so I became a really big believer in the whole self-help, you know, movement in helping people understand. And so, all of those things I write about, and and how how inspiring it could be, I think, for anyone, and no matter what their age.

R Rob Mineault 41:04

So you know we we've sort of covered a lot in terms of you know all of the things that have that have changed. I'm curious though about your perspective on where are we sort of at in terms of services and and building out processes for people who are who are newly diagnosed because it seems to me just even through this conversation but also just in in my own experience of my career that the ideal situation for somebody who's who's newly diagnosed there should be a bunch of different things going on that walks them through their journey. Because you're absolutely right; it can be very isolating for people. We've heard stories again and again. So you know that might be you know that they they should you know have some counseling when they're ready when they're ready for it, whether that's grief counseling or whatever. But there should be also like some mentorship, and then you know some training in terms of maybe it's rehabilitation, like daily living skills training, and then even assistive technology training. There should be a bunch of different things going on to really best service somebody who's newly newly diagnosed. Do you find that the system, and you know, and I'll see that in quotations, are we getting better in being able to provide these services to people, or is there still a long way to go in that sense?

T Tom Perski 41:34

Well, well, of course, I'm from the Stone Age, so it really was really was pretty brutal back then, right? And nobody was getting referred, and nobody knew the word. 'Low Vision' wasn't really in anybody's language, and either was macular degeneration. Nobody, if you ask somebody, no one ever heard of it. And I know it's hard if you're a young person to believe that's what the world was like, but it really was. And I remember being starting to attend the Ophthalmology and the Optometry conferences, and I was asked to be a speaker early on. And I remember the story that started being passed along, where some man had a prosthetic leg, he was referred to an Orthopedic guy and had lost his leg due to diabetes. Then, and it worked worked out really good. But then, when he lost his vision, he did not get a referral to any services, and he ended up he ended up suing the doctor, saying, "Look, you know, I was referred for my disability with my leg and never referred for my eyes. And I don't know if that was an actual case or somebody made that up, but it was it was it went to I think every eye doctor in the country. And I thought, oh, finally, you know, this this is going to make a difference, but it really didn't. It it just it just got better so slowly that it was pathetic. It really was pathetic, and I think we still have a long way to go. Of course, it's much better now, and I I believe people, you know. Well, of course, the internet was the was a huge jump, you know, because I'm talking about days before social media at all, or Facebook groups and all the things that people can get plugged in. But I think that might be the way that people find out. Still, you know, I don't think it's through their Ophthalmologist. Or I remember when the the American Academy of Ophthalmology, that was about seven or eight years ago, they put out a a video. The chairman of the academy put out a video saying that you know low vision services was really the best practices for any ophthalmologist And did it change? I just I have a feeling it's just it's just not anywhere near what it could be.

S Steve Barclay 46:37

Yeah.

L Lis Malone 46:38

Yeah, and you know I'm gonna agree with with Tom on that, and because here in the States, and probably me being from New York, and then Tom being from from Chicago, we we definitely had the benefit of being in in well populated city centers, but it always comes down to where you live, at least in the United States. And you know you're supposed to get referred to the state, and then you just have to cross your fingers that you get your file lands on the on on the desk of a really good caseworker, and that's always what it seems to come down to here. So it's definitely not a perfect system, and experiences are vary wildly from from case by case and and you know circumstance by circumstance because there is no there is no true across the board expectation. I mean, there's requirements that are kind of generalized, and each state might have a slightly different interpretation of what immediate services actually mean so, yeah. I feel like on that respect, because of that, it can be the the wild wild west in terms of getting services still.

T Tom Perski 47:50

Yeah, I think you're absolutely right that the services are great in in you know larger cities and cities that have you know like Optometry schools where they're training doctors in low vision, and there's a lot going on, and it's really really great. But in so many areas, not so much, you know. And so it can be it it can vary quite a bit, I think. And and then even though they might, someone might go to a low vision center. They might be referred and get maybe the proper glasses and magnifiers and so forth. It's different, you know. Every service level is different, you know. Or they don't have counselors. They don't necessarily, for sure. You know, they don't have an orientation and a mobility teacher. They they might not have a daily living skills teacher, and so people don't know that that's available or that's there are people that are trained and and very good at those services. And so, how do you find those kind of services? So I think that's another aspect that you know that's difficult for people.

R Rob Mineault 49:10

Yeah, yeah, and it's very much the same in here in Canada as well. You know, and maybe even worse because you know, really, we have one big organization that's a national organization, of course, CNIB. And then maybe you know, province, you know, province by province, you might have you know some some smaller organizations, or you have some advocacy, blindness advocacy organizations here and there. But really, in terms of service based organizations, we just got the one, and when you have a single point of failure, that's that has limited resources. Yeah, a lot of people, you know, aren't necessarily getting the the services that they need. But I think the other problem is that even when you do have multiple organizations, they're not necessarily talking to each other. There's doesn't seem to be sort of any network where you know one organization is feeding somebody, you know, providing services to one person, then passing them off to to another organization to help with something else. It can be very complicated, and then you know, of course, that it's it's complicated as well because depending on who you are and how old you are, maybe your needs are going to be different from from somebody else. So, yeah, I get that it's very complicated, and and you know the the resources are limited. But you know, I feel like I would agree with with both both of you as well. I think we we do have a real long way to go in terms of really being able to map out a really impactful service plan for for anybody who's newly diagnosed, it's it's it's a lot of the wild west here too.

T Tom Perski 50:50

And those years ago, I know that they did surveys and did quite a bit of research and finding what percentage of people actually access services, and it was very low. It was like 30% of all people who are vision impaired access services, and 70% actually don't. I hope it's better now. That's 10 or 15 years old data, but that's how it it has been you know, and the difficulties of well back then I remember every organization it seemed in the states was Chicago Lighthouse for the Blind or the Association for the Blind in New York you know everything was for the blind and people as you know, as we got into the baby boomers or whatever, they're not blind. You know, why would I go to an organization for the blind? I mean, that was a big deal back then, and people started changing their names, and that was a big thing too.

R Rob Mineault 51:57

Yeah, and you know, and we still fight that battle. I feel like you know, that is still a really giant misconception that's out there. Is that people really don't understand that blindness is a spectrum in terms of the general public, right?

T Tom Perski 52:08

Yeah, yeah, and the approaches of you know two organizations here, NFB and ACB, they see the world completely differently, and that's confusing for consumers too. Yeah, and and the approaches of helping and rehabilitating persons and so forth is like completely, you know, like the Democrats and the Republicans almost. And that that could be you know that could that could be a hindrance not only to persons and families but getting getting legislation or getting things passed that need to be passed to say you guys need to agree on getting things done the same if you don't agree why should we help you know

R Rob Mineault 52:59

Yeah that's right

T Tom Perski 53:02

but I won't go any further in that aspect of things.

R Rob Mineault 53:06

Oh, I know. Like honestly, like literally, I feel like we could talk to you for like three days, and we wouldn't cover everything that we could talk about. So, Tom, actually, one more thing about the book. So, I guess I just want to put this out to to the audience, get the book for sure. But who who is who's the book for, and what's sort of the sort of the underlying message that you'd like that that you hope that the the book will give people?

T Tom Perski 53:34

Well, that's a great question, and the book really, you know, we talk about low vision, and that's part of the the story. My story, of course, is a memoir. But when you start reading it, to me, I think the message I wanted to give to anybody going through any struggle at all is that there is a process behind what you're going through, and to believe and understand that process, and use that to go step by step, and hopefully inspire and give hope to any situation in life. You know, and of course, it's easier when you're vision impaired, you're reading a book about vision loss. But there are so many books that have been written about you know grief and loss and and losing a spouse. I mean, all the major things that happen in life, you know. And so that that was my goal was really to try to let people know that that there's a process. There's you can grieve the loss and you can go on, and and that allowed me to accomplish way more than I ever believed I could. And so I didn't write all you know. I didn't write any of my great accomplishments of. My 40s, 50s, and 60s, because that really wasn't the story. The story was more, okay, you know, how do you go through? How do you grieve? How do you bring life into balance, and then go on and do the things you your life changes, and you can go on and do the things you want to be able to do. So I hope it's helpful not only to young people for sure, but even even those who are older who are losing vision. You know that that there can be a life that's inspiring, and you can do many many things. You can travel the world. You can do things that you never thought you could when you're going through the loss, and you believe that you know in some ways life is over, and that's not true. It's just not. Yeah.

R Rob Mineault 55:52

So that's an excellent segue. The name name of the book, of course, is "There's No Vision Like Low Vision." Find it on Amazon, wherever you buy books. We'll include a link in the show notes, of course.

T Tom Perski 56:02

And for those who who use like Kindle, it's available on Kindle. Okay. So if you put it on like the Kindle app, you know, on your yep iPhone or whatever, and then let the let the smartphone read it out loud to you. So that's you know a good way right now because it's not in audiobook form yet.

R Rob Mineault 56:23

Thank you so much for taking some time out and chatting with us. Anything else that you that you want to plug, where people can find you, or or what you're up to these days? Anything at all?

T Tom Perski 56:34

Sure, you can reach me at tom@macularjourney.com Is a little website that I have about Stargardt's as well as age-related macular disease and and or I you know answer all of my emails every day. It's been it's been great just being able to one or two times a day, just hopefully inspire people. So, feel free to write me. Thank you all. Thank you, Steve. All right. Yeah, thanks, Tom. Appreciate you. Okay. Bye. Bye. Bye.

S Steve Barclay 57:16

Yeah, I feel like we could do an entire show segment with him just on that grieving process, he talked about for people losing their vision.

R Rob Mineault 57:26

I agree.

S Steve Barclay 57:27

Yeah, that part really resonated with me because I see it all the time here. You know, I see people coming in and they're in tears. You know, they've just come from a bad diagnosis, and you know, they've been told, okay, well, there's a guy down there who can who can give you stuff that'll help, and they're they're just they're wrecked. You know, they're they're they're they're looking at a major life change, and they're they're just starting that journey. And like you said, you know, they they might not do anything to begin with. They might reject everything to start, but they come back.

R Rob Mineault 58:01

Yeah, it really - assistive technology. It's such a complicated field, just because of that. And you know, I didn't even think of the sort of the emotional component. But you know, you guys are absolutely right. Like I can see that really factoring in as well. You know, when somebody's sitting down trying to look at a piece of AT and they're completely overwhelmed like that. I mean, it's just it's it must be really a really challenging headspace to be in. But that's why his perspective, you know, is so fascinating because you know he lived it and then he went and he's doing it, and so you know having being able to talk to somebody like that that absolutely knows the questions to ask, or even can really empathize with the with the type of feelings that somebody's having when they're sitting down and and sort of looking at a piece of AT, or coming in for some counseling. It's just invaluable.

S Steve Barclay 58:56

That kind of lived experience is something that should be shared.

R Rob Mineault 59:01

Yeah. Well, you know, it's interesting at Blind Beginnings there's there's been a lot of conversation around the the counseling component because we do some some counseling stuff too. Shawn is a counselor as well, and you know she of course lives with with RP, so she has that lived experience, and I I really feel like that's a really interesting conversation to me about how important when you're when you're sitting down and you're doing counseling for somebody who is going through that. How important having that lived experience is, and how key it is. Because I don't know, I don't know that there are that many you know counselors with that lived experience out there, and I think that that is maybe a field that you know could really could really use some you know some people entering into it.

L Lis Malone 59:51

Well, the the other issue about counseling is that it is definitely limited in terms of availability. Without actual licensed counselors, at least in my experience, with the lived lived experience, so much of it ends up being peer counseling, and I guess is like the the next best thing. But then the layer that sometimes people forget about when you're talking about the counseling experience or the peer counseling experience is that even if you have the lived experience, there is there are always these additional barriers that individual people have to have to go through, and what one person's lived experience will be may not be the same as the other based on.

L Lis Malone 1:00:37

You know socioeconomic issues, family support issues, you know, access to education, access to technology, access, you know, to all those other things. So, I mean, it is absolutely important to have that for sure, to have that insight. But then sometimes people forget, like that there's that whole other huge component to it that can make two people's same air quote lived experience completely night and day.

R Rob Mineault 1:01:05

Yeah, yeah, I know it's very true.

L Lis Malone 1:01:08

And because I've actually experienced that myself, but but but I tell you though, a good licensed low vision lived experience counselor are like worth their weight in gold.

R Rob Mineault 1:01:20

100%. I think that really the the key is is having a a bunch of different services open to to you, like that includes counseling and mentorship, because they're both important, but they're very they're very different in terms of of what they're the needs that they're they're filling.

L Lis Malone 1:01:38

Yeah, I have been pushed into - when I say push, like I should say gently nudged - to, like oh, why don't you participate in some more of the like social events and you can meet more blind people or something like that. I'm like, well, that's like saying like, hey, you should go here and just hang out with white people, or you should hang out with here because they're all right-handed or whatever. It's like, well, there gets to a point where like, I okay. It's great to have people in your network, but I'm like, okay, hey, anyone else not wear the same color socks today? I don't know. Like, sometimes it's like you you know that the intention is good, but sometimes just integration without feeling segregated is a really important thing, and developing those relationships as opposed to so I feel like there's so many different extremes in all this, and I think it really comes down. It's like like kind of like you were saying, Rob. It's like you got to have like a like kind of a good sort of selection of varying available resources so that you don't have one, just one resource that you're that you're limited to, and one point of exposure for sure.

R Rob Mineault 1:02:48

Yeah, yeah, and that's the problem that we face here. Like you know, with one with one National blindness organization, it can't do everything.

L Lis Malone 1:02:56

Right.

R Rob Mineault 1:02:57

It just can't. It doesn't have the resources, and and honestly, it shouldn't. I don't think that one organization should try to do everything. I mean, I think that you know there's there's plenty of of room for for different parts of this of this journey and the support that somebody might need. Yeah, but it is it's it's very complicated. But that's why you know, man, we need like you know 12 more Toms. To be honest, like we need to download, we need to download his consciousness into an AI.

L Lis Malone 1:03:28

We're gonna upload him.

R Rob Mineault 1:03:30

Yeah, because honestly, like that that lived experience and and that set of of experience and perspective on you know what's happened over the last 40 years is just invaluable. So you know, I'd recommend for sure anybody go out buy the book. You know, especially if you know if if you or somebody you know is is newly diagnosed, definitely get the book. But we should get the book too.

S Steve Barclay 1:03:58

I've already ordered it.

R Rob Mineault 1:03:59

Have you?

L Lis Malone 1:03:59

I love that title. That is that that title is golden.

R Rob Mineault 1:04:03

I know, right?

L Lis Malone 1:04:05

It is

R Rob Mineault 1:04:05

Amazing. Uh, well, anything else to say about anything before we wrap this this puppy up?

S Steve Barclay 1:04:13

Oh no, I think that covers it.

R Rob Mineault 1:04:17

All right. Well, hey, Lis.

L Lis Malone 1:04:19

Uh, hey, Rob.

R Rob Mineault 1:04:21

You know where can people find us?

L Lis Malone 1:04:22

Oh, they couldn't find us at www.atbanter.com

R Rob Mineault 1:04:28

That's right. That is right, old holder of the cowbell. So that means that you are now the official cowbell person.

L Lis Malone 1:04:37

I can be the the cowgirl.

R Rob Mineault 1:04:39

Yeah. Okay.

L Lis Malone 1:04:41

Wait, wait. Wait. I'm a Giants fan. I can't ever say that. That was oh god. Like I'm disgusted. I feel a little gross. I think I threw up in my mouth a little bit when I said that.

R Rob Mineault 1:04:50

You'll be cowbell girl.

L Lis Malone 1:04:54

Yes. There we go. I feel better now.

R Rob Mineault 1:04:57

So yeah, maybe we need to get you an industry standard cowbell.

L Lis Malone 1:05:05

Yeah, sorry, sorry, Steve. I only have my AT Banter branded one.

R Rob Mineault 1:05:14

Maybe we just have my bite bullet and just go digital. I just have to like do a canned version of the cowbell. I don't know.

S Steve Barclay 1:05:25
Well, then we wouldn't be able to make snide comments about it when it goes wrong.

R Rob Mineault 1:05:28
That's true. Actually, that's true.

S Steve Barclay 1:05:30
It takes away comedic possibility.

L Lis Malone 1:05:33
I'm gonna rehearse.

R Rob Mineault 1:05:34
Okay. All right. Okay.

L Lis Malone 1:05:36
I expect to have a better a better strike next show.

R Rob Mineault 1:05:41
Okay, yeah, maybe it's just all about what you're hitting it with.

L Lis Malone 1:05:44
I know, yeah. I'm gonna, I'm gonna, I'm gonna sample some stuff. We're gonna work on this.

R Rob Mineault 1:05:48

Yeah. Okay, great. We all have homework.

L Lis Malone 1:05:50

Yes, have faith. There you go.

R Rob Mineault 1:05:57

They, they can also drop us a line if they so desire at cowbell@aatbanter.com See, I feel like that was better. That was that was that was good. You're yeah, you're already improving.

L Lis Malone 1:06:12

Okay, well, look at that. Check it out.

R Rob Mineault 1:06:14

Yeah. So you know, a couple weeks of work, homework, and we'll be golden.

S Steve Barclay 1:06:20

Cowbell Prodigy. Yeah.

R Rob Mineault 1:06:25

Steve, where else can people find us?

S Steve Barclay 1:06:27

Social feeds. We've got the Instagrams and the Facebooks.

R Rob Mineault 1:06:32

Yep.

S Steve Barclay 1:06:32

And what's that other one? Mastodon.

R Rob Mineault 1:06:35

Yeah. Whatever. Yeah, sure. Mastodon.

S Steve Barclay 1:06:38

Does anybody use Mastodon?

R Rob Mineault 1:06:40

I don't know. I don't. It was a thing, or maybe it was a thing for a while. And it's just if everyone's so fickle, everyone's on the everyone's on the TikTok.

S Steve Barclay 1:06:49

Yeah, except me. Except me.

R Rob Mineault 1:06:51

Actually, except I'm not.

S Steve Barclay 1:06:53

Yeah, my daughter my daughter saw me doom scrolling on Instagram one day, and she said, "Dad, you should get TikTok. The videos are way longer, and there's so much more of them. It's like that's the last thing I did.

R Rob Mineault 1:07:11
Exactly. Yeah, I'm becoming protective of the brain cells that I have left.

L Lis Malone 1:07:14
So all two.

R Rob Mineault 1:07:17
Sorry, what?

L Lis Malone 1:07:20
All two of them.

R Rob Mineault 1:07:24
We didn't have our our episodic dig, so that's good. We got that in just before the end of the show.

L Lis Malone 1:07:30
There we go.

R Rob Mineault 1:07:31
All right. Well, that is going to be about deal for us this week. Big thanks, of course, to Tom for joining us, and we will see everybody next time.

S Steve Barclay 1:07:46

This podcast has been brought to you by Canadian Assistive Technology, providing Low Vision and Blindness solutions as well as Physical Access solutions and Augmentative Communication Aids across Canada. Find us online at www.canasstech.com or if you're in the Vancouver Lower Mainland, visit our storefront at #106-828 West Eighth Avenue in Vancouver. That's one block off Broadway at Willow. You can reach us by phone toll free at 1-844-795-8324 or by email at sales@canasstech.com