LBS2E5- Meet me at the Intersection of... with Ben Akuoko

**Deborah:** Hi everyone. It's Deborah Gold here, executive director of balance. Before we begin, I just wanted to hop on and say a huge thank you to all our listeners for loving our content and joining us from around the globe. We are so happy to have you. We would love to keep our podcasts going. If you'd like that too, please consider making a donation, the link can be found in our show notes. Thanks for listening and enjoy the show.

**Ramya:** Welcome to living blind. I'm Ramya Amuthan, your guest host for today's podcast episode. The living blind podcast explores the perspectives and lived experiences of people with low or no vision, and delves into the barriers, challenges, and real life strategies that they have for living life to the fullest.

This episode is second of a three part series on the intersections of blindness and other lived experiences and identities. This podcast is brought to you by balance for blind adults located in Toronto, Canada. And this season of living blind is sponsored by accessible media, Inc. ... AMI. A bit about me, I'm the co-host of Kelly and company, which is the live afternoon show on AMI audio, focusing on lifestyle arts, culture and entertainment... and practically everything in between. I'm also the host of AMI audiobook review, which is a fresh new weekly podcast where we talk all things, audio books. Now for today's guest, who is a great friend of mine and an exceptional advocate in the blind and low vision community.

He's currently the CNIB program lead for advocacy and accessibility in the GTA. Let's welcome in Ben Akuoko. Welcome to living blind.

**Ben:** Hello Ramya. Thank you for having me today. I'm so excited to be on this episode, for sure.

**Ramya:** Yes. We have lots of conversations on the regular, so I'm really glad that the listeners of living blind are going to get to know you a little bit today.

So do you mind starting off with a bit of a self description? Anything that you want us to know about you at the start?

**Ben:** Oh, of course, of course. So I'm going to definitely start it off with I'm a person who lives with partial sight of course, is retinitis pigmentosa. I was diagnosed with the eye condition at two years old.

So my parents realized that I was having troubles in the dark and my peripherals were affected. I can see from my peripherals. And then also I'm going to throw in, I am a black male. Um, my parents were both born in Ghana, west Africa. So I am a first generation Canadian and I'm very close to the culture. Like even right now, I'm looking at, uh, I've gotten a flag, uh, across my room, so I'm very close and love the culture.

**Ramya:** Okay. Amazing. And of course, Ghanaian food is incredible. So, shout out! Your journey with RP, retinitis, pigmentosa it's I would say a gradual one. Would you agree?

**Ben:** Yes you are correct.

**Ramya:** Okay. Yeah. So like you've been diagnosed pretty young, but, um, the, the journey that you had with the actually experiencing some of the, the visual and practical symptoms of RP has been pretty gradual.

So can you talk to us about your teenage years going through integrated school systems? Uh, and you went through a lot of school. I think you're currently in school?

**Ben:** Yes.

**Ramya:** So your teen years compared to your twenties and as you live in your early thirties right now.

**Ben:** Okay. I loved how you asked that question because it has been a roller coaster and especially how time has evolved when it comes to accessibility and accommodations for us uh partially sighted and blind folk.

Uh, so when I was younger, I had quite a bit of vision. So I had enough vision where I could pick up a basketball shoot in through a hoop, catch a football from long range. So even the understanding of sight loss was kind of distorted. Where the fact that it was like, how is this person partially sighted yet I can throw him a football. Sometimes he catches it, but he doesn't catch it sometimes. So even with that whole paradigm of having some sight, but still being partially sighted with my parents who were, were from a culture where sometimes people look at disabilities as a little bit different, um, more sheltering, um, more we got to take care of him. It was like, he's still able to see so let's pretend that he has sight and let's try not to speak about it as much unless we have to.

So even going from my journey in elementary school, as you mentioned, being integrated in the mainstream school system instead of going to a blind school, I felt that I did really struggle because I did not use the resources and the supports that I should have. And I look back into this day and I'm like, thinking to myself, why didn't I use the resources offered? And then to, to add into that as well uh, technology's so advanced now, so I'm not trying to age myself, but even in the generation I grew up with, they still had things like CCTVs. Laptops weren't really around an elementary school. They weren't really offered. So just having the, the bulky equipment, which kind of made it hard to, to kind of go and thrive in school. So, uh, continuing onto my journey, I guess I'm just going to kind of fast track it where elementary school I really struggled with because coming to terms with, um, my disability, my sight loss? And then high school I also struggled because I was being told that no, don't give him that much of a course load. So, uh, we're going to stick to him having three classes a semester when all the other students have four. So yeah, with that, I found that, um, that almost potentially held me back until my parents actually kind of stood up for me and said that I'm capable of doing those four courses. So I was able to graduate within the four years of high school. So, uh, once again, to fast track, I went to, um, social work in college. So social service working so big mouthful. And, uh, from there I was able to kind of accept my sight loss and using the equipment. So from there, I felt like I really thrived in, as you mentioned, I'm in school right now, I'm doing my MSW part time so Masters of Social Work. So throughout my SSW and my bachelor's, I was able to find that identity.

**Ramya:** Well, you know, a lot of the things that you talked about in your journey, I am nodding my head too, because, uh, of the roles that teachers played, um, being in an integrated school system to begin with through primary school, middle school, high school, and then of course our parents and some of the ways that they've really played unconscious and conscious roles in our, um, lifelong journey with low vision.

And I think that. You know, as you're different, your journey is as different as it possibly could be from everybody else but also it can be very similar in terms of the relate-ability. Um, but some of the things that you mentioned, like setting the bar low, you know, people deciding for you that you can't necessarily have a full course load because of X, Y, and Zed reasons so let's just make that decision for you. And then somebody, um, who is differently supporting you coming in and stepping in and advocating for you and saying, ah, actually I think that he wants to graduate with everybody else and he wants to do academics like everybody else. Did you find now hindsight now at 33, you're looking back at those kinds of things, the ways that people advocated for you in potentially positive ways, potentially not so helpful ways. How did that play a role in the way that you advocate for yourself now?

**Ben:** Good question. And I love how you bring that up because within the culture, when I refer to the culture like ya, of course, I'm referring to, to my, my family Ghanian culture.

It was almost like I like to compare it where they, yeah. Independent. So, uh, things where they, I like to compare it to like throwing you out and seeing, kind of learning how to swim. So you learn to kind of advocate for yourself, young. You learn to know your needs, you know, how to speak for yourself. So it was very difficult, kind of looking back at it where you have two parents who are, uh, outside the country, like born abroad. So even the resources that were there, they weren't aware of it because they didn't grow up in Canada. They were used to the culture back home and, uh, for any resources or even any kind of spokespersons to let them know that, hey, these are the services that are available. These are what's good for, for young Ben at the time. So I found that sometimes with living within that culture, sometimes you would think, yeah, advocating for the right things, but sometimes it's the wrong things. Such as. I'm not going to use this equipment because I feel like it pinpoints me as being a blind individual.

So you almost still have that, um, that characteristic of advocacy, but you're advocating for the wrong direction. So I found a lot of that. Uh, also it's used in a good way because my parents taught me how to be very, very vocal to know what you want to know what you need. So just having that ability to advocate and say, this isn't working for me and this, this is not, not right for me, so I definitely learned that very young. And at the same time, being a child and being, being young, you have to learn how to kind of listen to the authority as well and take their suggestions as well. So it was a lot of that. So it was just, almost like a big cocktail of different... I guess perspectives to learn how to advocate.

**Ramya:** Yeah, definitely. And the way that everything kind of either comes together or doesn't come together really, depending on like what stages of life you're in right now. Because, um, as a teenager, a lot of us are just thinking I don't want mom and dad's help. I don't want to get on the yellow school bus and go home when everyone is walking home or going to the movie theaters. Right? Like it's just such a different way of life. For me I literally did not want to be seen with my white cane. Until 18 or 19 when I decided that, okay. Yeah, maybe this is just one too many steps to be falling down at nighttime. So let's just start using the cane, right? Uh, and then that's when you start to, well, that's when I started to put the puzzle together of identity when it comes to my white cane and how that plays a role in it. Um, but the same thing, you know, parents. It's that old saying of, um, we do what we think is best for you, right. We're always trying to do what's best for you and that's great. But when do you start doing what's best for yourself?

**Ben:** I totally agree. I... 100% agree. And I love the fact that you did bring up the little yellow school bus because I was once upon a time in that place. And it is almost when you do look back at it, you see yourself and, you know, you do have that potential, right?

So when I started working, uh, my old, or my first job, I was taking the bus just like everybody else, and it was that potential. So I think eventually with the support and also with individuals and family, having... having... okay... I don't have the right word, but having that, you can do it attitude. I feel like that really does help for you to be successful.

**Ramya:** Yeah. Yeah, absolutely. And even like you're saying you seeing that potential in yourself really does go back to the way that others helped you see yourself, right? Your parents, your family, um, huge mentors or role models in your life from when you're a kid or going through rough times, whatever it is coming to terms with all different parts of your identity, not just disability, but coming to terms, as, as you said, a black male with a disability. That's a lot of intersectionality to go with.

And, and I'm curious to kind of, um, move on to another focus, your love and passion and work in social services. You have a lot of work experience in social services. As you said, you keep going to school and learning more and keeping, um, that ear out for, for everything that's going on and how you can find your place in social services. Were you always good at listening to, to others, to other's perspectives, um, to kind of taking in what differences there are in the world?

**Ben:** Know what? I feel that having both my intersectionalities as being a black male, as well as living with partial sight, it made me empathetic to others. So it's almost, it's like fate that I have been a part of this, this field, because, it just feels like everything has been built up from my past. So, the question of you asking, have I been able to listen to others? I got to admit once upon a time I was a horrible listener. I would just be in dream town, just thinking about my own thing. You know, as a kid, me, me, me egocentric. But then I felt that having a disability such as sight loss, you become a little bit mature. You start to see people for who they are. You invite people with differences. You're not as judgmental as maybe you could potentially have been. So I found that being a part of the social service work field or the social work field, I guess I'm both being part of the field has really it's been a big benefit to have all these different intersectionalities, because I could identify with someone who is racialized. I can identify with someone who does live with a disability and potentially are seen as a certain way in, in societal norms. So a perfect example that I would make mention of is uh, the fact that, like, I know how it feels to, to, to be judged in certain circumstances or be treated a certain way that you're not. So yes, to that question.

**Ramya:** That is, um, such a, such a full circle mentality, right? Because you go through as a kid, um, or as a, as a new person with disability, you know, for some of our listeners, you might be going through, um, newer realizations and diagnoses and realities that are hitting really hard and the challenges are super hard to overcome. Um, all of us at one point, you know, going through the dark times, feeling this is, this is my problem. Nobody can understand. I'm very lonely. And um coming back later to say yes, but this is what gives me empathy in the end is, is a, it's a struggle. It's a big leap. It's a big hump to go over, Ben.

**Ben:** Exactly.

**Ramya:** Um, I want to talk a little bit about the stuff that's going on around the world right now. There's huge realizations, um, and tapping into horrific realities, histories. Um, probably around last year and the year before we started to recognize things that are going on in different communities... the black communities, indigenous people, people of color. So your skills of empathy, um, listening, the way that you've trained yourself and tapped into these, these parts of yourself, how did this help you to, to make your way in the, the kind of realities we're living in right now?

**Ben:** Of course. Obviously, I would say the lived experience for sure. So going back as living as a person with sight loss and living as a black male, We like to separate certain aspects and say that, oh, they don't touch each other, they have nothing to do with each other. When you go into an organization that only deals with disabilities, you should only stick with disabilities, no, don't speak about anything else. That's what you should do. Or if you go to a organization or institution or anything that has to do with race or religion, just stick to race or religion and culture. That's all you have to do. And I feel that all these years, that we all grew up with that mentality where even for myself, you mentioned role models. When I was younger, I just never saw someone who was black, a black male with sight loss. And people can go and say, oh, this, this, this, this, this, and this Stevie Wonder there's Ray Charles, but these are the people on TV.

But in front of my face, I feel like from five to 20, I, or even 26, I did not meet racialized people who had sight loss and even looking at today and what's going on all this talk about, um, all this talk about structure and systemic racism and ableism. And it is so true now that you look back where you just do not see role models in certain sectors of your life and certain experiences of your life. \And with that, That can really have a huge impact on the people who have to be exposed to this. So for example, if you don't see people in your positions or people like you doing things that you want to do, or having positions that you're looking to do one day, you sort of turn off. So even growing up in high school, I felt that I was so lost because even coming from the black side of it... yeah... I shouldn't be smart in because I'm going to get made fun of, I should be good at basketball. I should be good at football. I should be making tracks and all this stuff, right? Like, why should I be good at school? I don't see teachers like me. I don't see professors like me. I don't see anybody represented like me. Though in that sight loss, okay, maybe you could see some black lawyers. Maybe you could see people in your community doing well, who are black, but do they understand sight loss? So even getting that advice from those people saying, oh, you have to do this, this and this, well you understand like the barriers of having sight loss while doing that. And then even vice versa in the blind community. You gotta do this, this and this. Well, do you understand the barriers of living as a black male? So it was something that was just never addressed. Even where we're going in the future. When we speak about intersectionalities and we speak about people's different experiences, I find that we're going in such a good direction and you will see me on the front line promoting that fact that we have to touch upon experiences when we look at agencies and organizations, especially.

**Ramya:** Well, you know, there's a lot of different aspects of what you're talking about. One of them is just definite community building, right? Meeting people, not just seeing people on TV and in positions, which is super, hugely important, but also meeting people and having conversations with them about the real life barriers that the two of you face together because you experienced the same kind of intersectionality and that same sensation of being, um, like falling through the cracks. Right? And not being recognized, not being understood on all these levels of, you know, you can't understand what it's like to be a person with X, Y, and Zed barriers facing, uh, facing you. And the other part of it is to how much of the stuff is unconscious? You're not deciding whether you want to be a professor or someone in the media or the President of the United States when you're two and five and 10 years old. Potentially not, right? But you see those people and you unconsciously say you can't do that. You can't be that person because that person doesn't exist out there. So as fun as it is to trailblaze, right... to be, to be the first one out there to do all these things, um, it really is so much more complicated than we even recognize at this point. Like I'd say only in the last year, year and a half, we've even been having these conscious conversations about what it is to not have representation out there.

**Ben:** Exactly. And I love how you mentioned, mentioned trail blazing. Trailblazing is not easy. It is not,

it is definitely not easy. I feel like there is that assumption where it's like, if you want something done, then you do it.

**Ramya:** Yeah right.

**Ben:** When you're put in a place where it's just no groundwork set down, it's a very shaky, it's very draining. It takes a lot of, out of a person to, to break that new ground.

**Ramya:** Right. Who do you go to if there's no mentorship uh, on where you want to be? At something to grab onto... somebody who says, okay, I get where you're coming from, let me help you build that up for yourself. If there's not that person to empathize with, um, you really can feel like you're just trying to tread water.

**Ben:** Exactly.

**Ramya:** Speaking of treading water, Ben, um, it's really important, especially during the climate that we're living in right now with all the COVID, et cetera, um, to talk about self care. So you do prioritize a lot of self-care, as far as I know when you're not working, you take part in a lot of, um, physical adventure, physical activity. And, and I want to know, has that really played a huge role for you during COVID times?

**Ben:** I got to say that self-care is so important even before COVID, even just like in general. Like society, it's just so much going on. Things are moving so fast. And I guess it's pretty ironic because with the pandemic, things are slowing down and people are going cuckoo kaka, right? Uh, so I feel like it's very important. Uh, I found, I guess I'm going to go through what I have done, like previously before COVID and what have I, or what I have done during the time. I think it goes across the board... physical fitness. Physical fitness is so important. I know we're at home during this time of recording the gyms are closed. But at the same time, you don't have to be at a gym. You don't have to be... I know Ramya you can relate to this benching 300 pounds.

**Ramya:** Totally!

**Ben:** I seen you squat. Oh my goodness people! Uh, so the gyms don't have to be open. Like you could just do things at home. You could do light impact work. If you're not an athlete, even just going for a walk, even going up and down stairs. It's so many things available.

Also, another thing that I find very important is self-reflection. And something that I do for self-reflection is journaling. And everybody's probably like, oh, journaling, I keep a journal. But at the same time, I, and I was telling this to you Ramya, where before the new year came up, I went back and I reviewed, like the nerd I am, I reviewed the whole entire year. And that feeling I got... and that feeling of accomplishment... that feeling of understanding where I came from with the lows to the highs and maybe the lows again, plus the highs again. And people I've met throughout the years to get the happen to my family or friends. When you revisit those times, you revisit places that you were once upon a time and it shows you the accomplishments that you have done throughout the year. So you don't know exactly the progress for sure. So. I think it's so important to journal. Uh, it's so important to meditate. Give yourself some time away from your phone away from like television, and then also reward yourself for the good that you have done. So if you, me being in school, I have, um, my assignments, uh, with that said, when I complete assignment, I treat it like, I just won an NBA championship.

**Ramya:** Nice!

**Ben:** Because you have to reward yourself for the hard work, even if it's something small, something small does lead to something big. So like I guess to wrap everything in a nice little bowl... bow, um, what you should do, exercise, reflection, meditation, and just be good to yourself.

**Ramya:** Okay. And the good to yourself part that can include like Netflix and binge eating...

**Ben:** Of course, of course, if you do it in moderation.

**Ramya:** Yeah. If you got your, uh, if you bench your 300 pounds successfully, then you can move on to the chocolate cake. I love it. I love it. No, I really appreciate you talking about that. You know, all jokes aside of course, it's nice to have some just chill, relaxed recreation time. But, um, when you're talking about meaningful self-care, that is the exercise. That's combining the mental with the physical and going out and getting fresh air going on your walks, uh, climbing a few stairs a day, you know. It's, it is really... I think sometimes we underestimate how much physical health plays a role in our mental health. And it's um, fantastic. I know everyone who's missing the gym right now, uh, can attest all that.

**Ben:** Actually to add one more in and something that we were just doing... laughing... just sometimes laughing just does something to you.

**Ramya:** Yes. I totally agree. Ben, before we let you go, where can people find you if they'd like to interact with you on social or anywhere else you'd like to send our listeners?

**Ben:** What people can interact with me on, because with the CNIB, we're pushing a lot for advocacy and accessibility, and even just that discussion of diversity and inclusion. So what you can actually do is visit the CNIB's webpage and we have a diversity and inclusion web page, and we're adding more and more and more. So for the people out there who feel... just not being just identified with sight loss, but just more intersectionalities, whether it's a part of the LGBTQS community or a different culture, different religion, visit our webpage for sure. The inclusive, diversity and inclusion web page on the CNIB.

**Ramya:** Amazing. And I'm really personally looking forward to a lot of the work that's happening, um, in this context through the CNIB and a lot of work that you'll be doing and continue to do in the near future. So, Ben, thank you so much for joining us on living blind today.

**Ben:** Of course. Thank you for having me and yeah.

**Ramya:** I appreciate you.

That's it for this episode of Living Blind. Thanks for tuning in and getting to know Ben Akuoko. And of course we'll put the webpage to the CNIB diversity and inclusion page on our show notes. A special thanks to Ben for being our guest. The two producers on the living blind podcast, our outgoing producer, Troy Taylor and incoming producer, Jeffrey Rainey.

The entire team at Balance, thank you for your support. And if you like what you heard today, subscribe and follow us on whatever platform that you're listening on for this podcast. We're also on Facebook, Instagram, and Twitter at balance for blind adults. To access the show notes, the transcript of this episode, and to learn more about Balance, visit balance fba.org. That's balance fba.org. I'm Ramya Amuthan the host of today's episode. And this has been Living Blind. Thanks for listening.