**Meet Haben Girma: The First Deafblind Harvard Law Graduate**

Transcript of interview on 20 April 2020 with Haben Girma and Nas Campanella.

This podcast is presented by the UNSW Centre for Ideas in partnership with the UNSW Disability Innovation Institute. Supported by the Auckland Writers Festival.

Kara Jensen-Mackinnon

Hello, I'm Kara Jensen-Mackinnon, Digital Producer at the Centre for Ideas. This conversation between Haben Girma and Nas Campanella was originally going to be a live event at the University of New South Wales, Sydney. Fortunately, both Nas and Haben were kind enough to record that interview over Skype. Throughout the recording, you will hear the sound of typing which is Haben's Braille computer. Nas asked the questions which are typed into a keyboard and then converted to Braille for Haben to read. On behalf of the Centre for Ideas team, I hope we can come together and share ideas again soon. But in the meantime, we have a world of podcasts and livestream events being recorded and published every week. So, stay tuned.

And now here is Nas Campanella and Haben Girma.

Nas Campanella

It is so wonderful to be able to talk to you. Let's start off by talking about this strange world that we are currently living in, the world of the Coronavirus pandemic. How have you been coping?

Haben Girma

I'm in California and here, everyone's been ordered to shelter in place. That means most people, people who want to follow the rules are staying home. People with disabilities have encountered various struggles related to that. Some people rely on in-person communication like the Deafblind community using tactile communication. So, the ability to go and do essential services becomes more difficult when you don't have access to those things. I've been staying home and relying on tech as much as possible, and delivery services as much as possible.

Nas Campanella

I'm a little bit the same here in Sydney, Australia. It's been a really strange time. We've been in lockdown for a few weeks now and most people are starting to really stay at home. We're allowed to head out of our houses once a day for exercise, or to go and buy food and things like that. But in terms of all the cafes and restaurants, everything is closed. And so, it's been, it's been… it's taken a little bit of time to get used to. I think for me, I'm still actually physically coming into the office to do my job because I obviously work in radio and need the equipment or facilities. But I, I've heard from lots of other people that it is sort of starting to get to them, that cabin fever feeling. Are you feeling a sense of that as well?

Haben Girma

I am going out every day and walking. And walking more than I used to, actually. I now walk about three miles every day and it's become the highlight of my day. I really appreciate being able to smell all the flowers we have blooming in this area right now. Lots of jasmine, do you have jasmine in Sydney?

Nas Campanella

We do. It's one of my favorite scents. I love it.

Haben Girma

Me too. I drink a lot of jasmine tea.

Nas Campanella

Oh, that sounds amazing. And in terms of the disability community, what have you, um I guess been talking about with some of your peers who also live with a disability in terms of how this has impacted them specifically? I know for me, for example, I usually take somebody’s arm to get around unfamiliar places and for me, that's meant maybe not doing that as much — or wearing long sleeves so that there's that reduced skin on skin contact.

Haben Girma

I think a lot of people are staying at home whenever possible. And in terms of going to places around their community, before the pandemic started people have systems in place. Maybe someone knew the route to get to their local grocery store with their weight cane or a guide dog. So, they would probably still use the same route, though it's advisable whenever possible to use delivery services or find alternative ways so that you're minimising being in contact with people. One of the biggest fears right now within the disability community is the medical community not thinking our lives are worth saving. Ableism is the idea that disabled people are inferior to the nondisabled. We're not inferior, but that idea is widespread, including in the medical community. So several states put out policies, saying, if we reach a point where we're struggling to get enough resources to people, we will refuse services to people with intellectual disabilities, or people with spinal cord injuries, and advocates have protested that. The specific states in question have pulled back their policies. But then there's still more states to work on and more places where this is a problem.

Nas Campanella

I've heard very similar things. Lots of people within the disability community talking to me and stories I've done over the past few weeks about the fact that you know, they're nervous about having support workers in because they might have a compromised immune system already. And this pandemic, I guess, heightened that nervousness around them, having people in and out of their homes and getting, I guess, more sick. And I think that's definitely a concern that seems, around the world in the community. Would you agree with that?

Haben Girma

Yeah, that's definitely a concern. Then there's also the concern of communication access once you get to the hospital, if you have to go to the hospital. Some people need sign language interpretation. Some people need tactile sign language interpretation. And there are fears that Deaf and Deafblind people will not get communication access at the hospital.

Nas Campanella

Yeah, look definitely some widespread issues there that we do need to canvass obviously now and use as a way of, I guess, learning for the future. If this has to happen again, or similar emergencies I think these things could be applied to even you know, we have lots of bushfires here in Australia. Whether it be tornadoes in the US, do you think it's something that could be applied to other emergency situations?

Haben Girma

Advocates have been saying for a long time, when looking into emergency preparedness, “Plan for people with disabilities!”. Pandemics, fires, all kinds of emergencies. Plans need to include access for people with disabilities.

Nas Campanella

If we move on to, I guess, you know, away from the pandemic now. Can you talk me through what your childhood was like?

Haben Girma

What a new topic! What was my childhood like? You read my memoir right, Nas?

Nas Campanella

I did! I absolutely did. And I loved it.

Haben Girma

I'm really grateful you took the time to read it. How did you read it?

Nas Campanella

I read the audiobook, so I got to listen to your beautiful voice.

Haben Girma

That was quite a struggle, actually. Originally, I was not scheduled to read the audiobook. Originally, they were going to have someone else read the audiobook. But I advocated. I said I wanted to read my own story. So, we embossed the book in Braille. And I read the book in Braille and they recorded me reading the book.

Nas Campanella

I'm so glad you did. It's only fitting that you totally 100% own your story because it is your story. Everyone else usually reads their own audiobook. So, I'm so glad you pushed to do the same.

Haben Girma

Well, my book is all about advocacy, and people speaking up for their rights and going after their dreams. So, even the process of creating a book, writing the book, getting the book out, media, marketing, all of that was full of opportunities to advocate and increase opportunities for the disabled.

Nas Campanella

Absolutely, and I assume you know, you might have done some book tours prior to the pandemic lock down as well. What was that like in terms of making sure that spaces were accessible for people?

Haben Girma

There are different elements to making book events accessible. So first of all physical access. We want the spaces to be wheelchair accessible, the audience space and also the stage — because sometimes it's disabled people who are interviewing me. And if they happen to use wheelchairs or need sign language interpreters, all aspects of the venue should be accessible. Then there's communication access, making sure there's a sign language interpreter present, putting out in the flyer that if people need accommodations, here's the number and email address that can be contacted. Because the deaf community is very diverse. Some people don't use sign language. I personally do not rely on sign language. English is my strength, I prefer reading things in braille. So, flyers should ask people, “’What accommodations do you need?’, here is the phone number and email address to contact”.

Nas Campanella

You're very much, I feel, a trailblazer in this sort of space when it comes to making books and events completely accessible to everyone no matter their circumstance. So, thank you on behalf of our community for doing that, we really appreciate it. I really encourage everyone to read your book. You've been so generous in sharing your story, but also your, I guess, advice for the nondisabled community as well.

Haben Girma

You, too, Nas! It takes a community to make our worlds more accessible. Stories like this. You taking the time to have this conversation and help promote disabled voices that helps shift our culture and allow people to recognise ableism and help do the work to dismantle ableism.

Nas Campanella

Absolutely. And look, let's dive into some of the stories that you share in the book. Tell us a little bit about your childhood. What was it like growing up?

Haben Girma

I was born and raised in California. My parents are from Eritrea and Ethiopia. During the summers I'd go to Eritrea, and the culture is different there, naturally. I had to readjust to different expectations, especially to expectations for women. They really wanted me to cook and I said, "no, I don't like cooking". But finally, there was a point where everybody in the community, everyone in my family was chipping in to help at the wedding. My mum said, "you have to help with your aunt's wedding, we want you to cook". And I said, "I'm happy to support the community, I want to participate, but not cooking. What are the men doing? What chores are they doing? I'll do those chores.". My mum thought about it and said, “okay, follow me”. I followed her to the front yard. There was a group of men sitting around a table. She told my uncle, “Haben is going to help you”. And I told her, “wait a minute” — there was a strange smell in the air. “What are they doing?”, and she told me, “they're chopping meat for the stew”. After advocating that I did not want to do gendered chores she still made me cook! So, I sat down. I joined the group. I reached into the pile and brought out chunks of meat. They had slaughtered a bull, and everyone was participating and chopping it to make meat for the stew. All around me people were talking and laughing. I couldn't hear the conversations. Deafness is a spectrum. I could hear enough to tell that they were talking, but not enough to catch the words. And it was frustrating to be sitting with my family and not being able to participate, not being able to join the jokes and the laughter. I reached into the pile, got meat, chopped meat, and I tried to tune out all the laughter and merriment around me. I hate being left out. I hate exclusion. I *hate* cooking. Finally, I tried to zone into just working. And I was reaching in, chopping, reaching and chopping. Then a cousin screamed. I looked up, looked around. I couldn't figure out why she was screaming. She got up and left the group. No explanation. And so, I continued chopping. But something was strange. I put down my knife and I was feeling a strange piece of meat, and then my heart started pounding. It was the bull’s penis! I was horrified. Maybe it was a joke that they wanted to scare the girls. Well, I'll show them I'm not afraid. So, I picked up the knife. Then one of the guys came over and took the thing away. Ever since then, whenever my mom asks me to cook, I just tell her, "remember the bull".

Nas Campanella

It's yeah, I knew you were going to tell that story. It's quite indicative, I guess of how you were an activist from very early on, I feel. I wondered where that sort of came from?

Haben Girma

I grew up hearing stories of activism within my family. My mum grew up during the war and they were told, “Don't speak your language. Forget your culture”. And they were supposed to only speak Amharic, the Ethiopian language, and adopt Ethiopian culture and ignore their own language, Tigrinya and try to think of themselves as a completely different culture. So, they were resisting in small and big ways. People were joining the freedom fighters. Those were the stories that I grew up with. That moved me to build up resilience. And when I feel something is not right, I question, I resist.

Nas Campanella

You took an independent trip to a particular country that most people will never go to in the world in their lifetime. And I wondered if you could share that story with us because I think it's quite indicative of you, I guess exemplifying to your parents that you weren't dependent and you wanted to do life, your own way.

Haben Girma

That's a really fascinating story. So, I've told you, my parents are from Eritrea and Ethiopia, which are in Africa. When I was in high school in California, I came to my parents one day and said, I want to go help build a school in Mali. Mali is in West Africa. Yet my parents were saying, "No, it's not safe. It's too dangerous. You can't go”. And I told them, "I want to help make the world a better place”. I want to help 800 school-aged children build a school so they can get an education". And my parents said, "No, it's too dangerous. You can't go”. They were very aware of all the dangers. They asked me, "You're blind, you can't see, how are you going to build a school?". And I told them, "I'm not able to see, but I am able to lift bricks and shovels and dig, just like the nondisabled students. American students don't know how to build a school. We're going to be learning together". My parents still said, “no”. So finally, I reached out to the program manager. There is this assumption that disabled people don't know their abilities. So, I thought maybe the nondisabled adult could talk to them. Maybe they would believe that they would believe me. So, the program manager sat down with my parents for lunch, and she listened to their concerns. “How is she going to build a school? What about malaria?”. And she addressed all their concerns. Finally, at that point, they agreed to allow me to go to Mali for three weeks — living in a village and building a school. I went, I helped build a school. I was out in the Saharan sun, digging for hours. It was exhausting work. When I came back, my parents had higher expectations for me, but just a little. They're still to this day, worried about all the dangers in the world. They're still going to be parents.

Nas Campanella

Yeah, look, I think that's an interesting point to make. I know my parents at times have been quiet, I guess, hesitant with some of the decisions I've made and places I've chosen to travel. And, you know, I've gone to, to lots of different places on my own. And I know when I broached the idea with them about, you know, for example, going to Turkey on my own to travel and, you know, they, I guess, they hadn't had any experience of disability before me, and I suppose they, they'd come from a traditional kind of sense of what disability meant, and what people could do. And I think unless you show your parents or communities that there doesn't have to be a huge difference in the things, we do the lives that we lead, I just don't think they have a comprehension of that. Which is really sad. But I think in this case, how do you think this sort of changed your life? It seems like this trip really was kind of transformative?

Haben Girma

Travel is transformative for all of us. We learn more about our homes and ourselves when we put ourselves in uncomfortable, different situations. Challenging ourselves to step out of our comfort zone helps us grow, especially when we're at that age of high school, 15 and really still growing. Though we truly never stop growing. How did you convince your parents to let you go to Turkey?

Nas Campanella

I came home one afternoon I had booked the trip. I mean, I wasn't a high school student. I was, you know, finished with the university and my first year of work, and I came home and showed them the tickets. Basically, there was no choice. There was no going back. And I think what's important to note is that once that decision was made, and I've made it, you know, They just said to me, "okay, let's put everything in place to make sure that you're safe and you're going to be okay". And I think that was what it was – definitely transformative for me.

Haben Girma

Yeah. I've also been to Turkey, but very, very briefly. Just for a few hours when I was coming back from Ethiopia one time. I love the food! The pastries and the coffee!

Nas Campanella

Oh, the food is sensational. All that rosewater and honey and the textures, the nuts they have lots of nice sort of nuts and flaky pastry and yeah, it's beautiful food.

Haben Girma

Yes! Do you still eat Turkish food? Do you get a lot of Turkish food in Sydney?

Nas Campanella

We do get quite a lot in Australia and its sort of very meat based I find, and I'm a vegetarian, so you know, but I can definitely get access to like lovely Turkish cheeses and salads and things. But there's a lot of Turkish restaurants here, which is fantastic. What about over there?

Haben Girma

Well, I am based in the San Francisco Bay Area and there's so much respect and appreciation for alternative eating styles. So many of the restaurants here accommodate different diets: vegan, vegetarian, gluten free.

Nas Campanella

Oh, that's fantastic. Um, one of the other sort of really exciting things that you have done is studying at Harvard Law School and I wondered if you could talk us through how you decided that you would go there.

Haben Girma

Originally, I wanted to go to law school in California. I didn't care about Ivy Leagues or how prestigious the school was. I just wanted to go back to California because I was studying, I went to undergraduate in Oregon, which is more rainy compared to California. So, I wanted to go back home. And then my Law advisor told me that at that time 2009 a lot of Law students were struggling to find jobs. And if I wanted to increase my chances of getting a job, I should try to go to one of the top schools. So, I followed his advice and applied to many of the top schools. Harvard offered admission and originally, I was not excited about the idea of going to snowy, cold Boston. But I figured it would only be for three years and there would be lots of resources and job opportunities once I had a Harvard Law degree, and the advisor was right. I definitely had more opportunities, having chosen to go to law school.

Nas Campanella

You mentioned resources, talk me through some of the resources that were at your disposal at Harvard in order to study?

Haben Girma

For example, grants. I needed to take out loans, but I was also able to get some grants to help reduce my student loan debt. There was also a lot of job opportunities, we regularly had networking events with law firms or public service networking events with non-profit organisations for people who did not want to go into corporate law. So, there were lots of opportunities, speakers coming in, great Professors.

Nas Campanella

And what about resources specifically to helping someone with a disability?

Haben Girma

Oh, you know, I did not know about that at the time. When I was choosing college, that was a huge factor. I was looking at four colleges. One of the colleges told me, “You know, we don't have a Braille embosser. We don't think we're going to be able to Braille your books. Or even if we did Braille your books, they probably wouldn't get to you on time”. That was someone from their disability office! That was incredibly discouraging, and I did not want to end up there. Whereas the school I eventually went to, they told me, “We don't have a Braille embosser, but we'll get one. We'll learn how to emboss your books, and we'll make sure they're on time”. And that summer, they got a Braille embosser. They trained one of their reading specialists to learn how to produce Braille, and she worked with all my Professors to make sure all my reading was available in Braille. That's how it should be. The school should do the work of making material accessible. Too many schools put the burden on students with disabilities to struggle and juggle making their work accessible on top of studying, which is not fair. I didn't know what Harvard would be like, I was just concerned about employment, because I had faced the horrible struggle of employment discrimination and employers assuming you can't do anything. Even, even if you absolutely have the skills, they still assume you're incompetent. So, I figured I'd increase my chances of getting a job if I went to Harvard, and I'll just figure out what the disability accommodations are like once I got there. I was lucky. They did a great job providing me with access to my course materials, braille and digital materials. If something was inaccessible in class, they would get it accessible. I had interpreters to also make audio content, lectures, class discussions accessible for me. Harvard wasn't always like that. There was a time when Harvard wouldn't even allow a woman in. Helen Keller said she wanted to go to Harvard. But back then they wouldn't admit women, only men. Over time the community changed, and Harvard opened its doors to women, people of color, and people with disabilities. They still have more work to do. There are still barriers at Harvard. It is up to the community to continue dismantling barriers, continue striving for inclusion.

Nas Campanella

I think something that struck me when I was looking at different universities to apply to, you know, 10, even 12 years ago. I was struck by the fact that some universities seemed well equipped with great disability services departments and when I went and met with a couple of the managers, from the departments at different universities, some seemed to be better setup than others. I think one of the problems I had was it was hard to determine or to weigh up, do I go to the university that is the best for the degree that I want to do? Or do I go to the university that will provide the support that I need? I think it's just so unfair that you have to sometimes choose between those things. How do we change that?

Haben Girma

We change it through advocacy. Not everyone is in a position to advocate. I absolutely respect that. There have been times when I felt too exhausted to address an unfairness. But if someone has the time and resources and energy, they should advocate when they recognise a school is denying access to students with disabilities, or their math program is turning away blind students because they feel blind people can never be mathematicians. Math and sciences is an area where a lot of schools are failing to provide access for students with disabilities.

Nas Campanella

Talk me through the social aspects of college life and of being at Harvard and making new friends.

Haben Girma

I went to college at Lewis and Clark College in Portland, Oregon, then later went to law school at Harvard. There were so many changes throughout that time. Middle school through to college I had almost no friends in school. It was really difficult to make friends. In middle school, everyone's focused on being cool. When you're different, when you're obviously disabled people are reluctant to connect, because they feel they won't look cool. At least in middle school. At least that was my experience. So, it was really lonely and frustrating. I know people were socialising around me. I read books, I knew what middle school and high school were supposed to be like – full of friendships and sleepovers and parties. But ableism, assumptions of incompetence made it really, really difficult. In college, things were a bit better. But there was still the fear of the unknown, of wanting to appear cool. So, it was really hard to connect with people. I kept trying. In my book, I talk about the process of trying to connect, and, and people being polite on the surface, but you can tell its condescending, and that they're not really being respectful. That was really frustrating. After a few months, maybe I think it was in the second month, I finally found my group of friends, very serendipitously. They were people who were interested in growing, interested in new things, things that are different. Learning about Eritrea, learning about disability access and they became my friends through the rest of my college career. In law school, I found that people are more mature. A few years had passed since college and people were ready to be more authentic and learn from each other and learn from difference. Rather than being afraid of difference.

Nas Campanella

I sort of had very similar experiences as a young, very young child, I guess. People feeling, I guess, uneasy to approach me in the same way they would approach nondisabled children I guess, in the playground or to make friends. Do you think that stems a lot from I guess, nondisabled children or society? Generally, not I guess seeing people with disabilities everywhere they look. You know for a long time you would open a magazine and you wouldn't see someone with a disability, you turn on the television and not see someone with a disability. I often talk about wanting a world where no matter where you look, whether it be the catwalk, the shops, your workplace, wherever it may be, that you see people with disabilities living full and active lives. I think, for me, once we change that sort of stigma, then I feel like it will be a lot easier for people to interact with us.

Haben Girma

Yeah, it's really, really hard to get over their fear of the unknown. I've heard of people who are so concerned about being offensive and saying the wrong word that they never approach, and they miss out on learning an opportunity. I always tell people, “ask”. Let yourself ask those questions. Then you'll realise what those terms mean, you'll learn the stick is called a key, or how guide dogs work, or how to communicate with someone who's Deafblind.

Nas Campanella

You have gone into the space of disability human rights. Tell me, I guess how you've seen that space progress in the last couple of years?

Haben Girma

So, we use litigation and various tools available to create change. We try to choose the cases that will make the biggest impact and change our culture. Ableism is the idea that people with disabilities are inferior. This is so widespread, that a lot of people do it without being aware of it. So, they have no idea that they're creating barriers. It's never occurred to them to stop and ask, “Is this a barrier?” Who's being left out of our community?”. You'll get store clerks that say, "Why should I make my store wheelchair accessible when we've never had customers with wheelchairs?". Well, if your store is not accessible, of course, people with wheelchairs are not going to be able to get in. So, there are so many layers there. It is important to address those layers. I try to start out by just educating people, letting them know the barriers exist and asking them to remove them. If they don't remove them. Well, there are consequences.

Nas Campanella

Looking to the future. What do you think are the biggest sort of barriers that are facing the disabled community?

Haben Girma

AI is incredibly powerful. And it's being designed and built without consideration for disabled voices. We need more disabled engineers, designers, testers, the people creating AI need to be diverse. There needs to be lots of woman, people of color, and people with disabilities to help spot the biases that enter the algorithms. I'm concerned about future tech, that's going to have layers and layers of barriers because of the biases in the creation process. So, we need schools to make their math and computer science programs accessible so that more disabled people can get into these fields and participate in the design process. We need the tech companies to increase hiring of people with disabilities. So, we have more diverse design teams.

Nas Campanella

Haben, on the issue of innovation, can you explain to us the communication device that you use?

Haben Girma

In this conversation we're using a Braille computer and keyboard. As you speak, Gordon is typing what you're saying and I'm reading the words in Braille. It's a standard QWERTY keyboard. I use the system because most people can type. Not everyone, but most people are able to type. So, I can put a keyboard in front of them, ask them to type what they're saying, and I'm able to read it in Braille. I wanted a system that allowed me to be able to communicate with anyone at a coffee shop, at a bar, at any kind of situation. Sign language unfortunately takes time to learn. Not everyone has the ability to immediately start signing the American Sign Language alphabet. Then, of course, there are different sign languages in each country. And Australia has a different sign language. Have you ever learned any Australian Sign Language (Auslan) Nas?

Nas Campanella

I have learned a little bit. In fact, I went to film a TV story earlier this week, and the person I was interviewing was Deaf. So, I had a friend come over to my house the night before and quickly help me brush up on at least the alphabet. So, I did a lot of finger spelling. But I wanted to make the effort to at least say, "Hello, how are you? And thank you for the interview.". We obviously, of course, had an Australian Sign Language interpreter there with us for the interview, but it's a beautiful language and I love how expressive it is and that I get to use my hands and my body in a different way. That's very unfamiliar to me as someone who is blind, I obviously can't look at sign language and the hand actions or facial expressions. So, it feels really lovely to be able to interact in that way. I first learnt a bit of Australian Sign Language when I was working in the Pacific with a woman who was Deaf, and we spent a month together, and she was my boss on an volunteer project we were doing at a group of disability special schools and she taught me a lot and I felt like I got quite good. But then it's that typical thing of you lose what you don't use, isn't it?

Haben Girma

I use some American Sign Language when I'm around people who sign. For example, Deaf friends. They might type to me and I might sign back or maybe when we're walking, we might be signing and walking. When I sign, I hold my hand over the person's hands and feel their signs. Tactile sign language.

Nas Campanella

Yeah, that's some. It's lovely and I love how, how you can still walk and talk and at the same time, it's, it's amazing.

Haben Girma

(Laughter). Then there's also Protactile. So, if your hands are full, maybe in one hand, you have a cup of tea, and another hand you're chatting with someone through sign language or maybe reading Braille. But Protactile, someone can signal on your shoulder or back like emotional or environmental information: smile, applause, someone has just entered the room. There are signals that can be communicated on shoulders, back, arm, anywhere on the body, really. If the hands are occupied.

Nas Campanella

So, is it in a sense? I guess drawing the perhaps images of a smile for example, on your back?

Haben Girma

It's a combination. So, you can draw a question mark to signal someone has a question, or is making questioning eyes, or waiting to ask the question. There is a signal for a smile, which is drawing a smile. Then you tap a person with your hand to signal applause. Round of applause can be tapping all around the back. So different combinations of drawing and movement.

Nas Campanella

Yeah, that's why I love it. It's a real expression. It's, yeah, it's just a beautiful language. And it's so unique I guess to the person I'm assuming and please correct me if I'm wrong, but the tactile signs, particularly?

Haben Girma

You probably already use some of it. When you do human guide, sighted guide with someone, and you're holding their arm, you can feel through their arm as their body changes. as they raise their shoulders in a shrug, or they squeeze their arm to themselves to indicate alarm, or to ask you to hush for a moment. So, there are lots of different ways Protactile is used, even if it's not consciously labelled Protactile.

Nas Campanella

I yeah as a sighted guide technique, I would obviously be able to tell if a person is putting their arm behind their back that I should step behind them because we might be going through a narrow space. You can tell a lot yes, absolutely. From somebody's movement.

Haben Girma

Yeah. What else do you have? Any signals that you've developed with your sighted guides?

Nas Campanella

Definitely. The one where to get through narrow spaces is one. Often I've had situations where I'll be chatting to a friend or a colleague while we're waiting for an elevator, and then we'll hop in the elevator and to signal that we need to be quiet because you know, we might have been talking about a particular person who is now in the elevator with us. So, to signal for me to be quiet now as you know, a bit of a pressed elbow towards the side of their body and my hand will sort of get crossed in between. I'll know, okay, it's time to obviously be aware of surroundings. I think something else I find difficult is: I might be walking along using my cane in an environment that I know very well, but then if someone comes up to me and says, “hi” and wants to have a chat. All of a sudden, I lose my sort of ability, I guess, to be able to multitask and have a conversation with them plus, continue knowing where I am. So, I often do take their arm as well at that point, just so we can continue chatting. But I can also continue on my way if we're going in the same direction, if that makes sense.

Haben Girma

Yeah, I feel like there's standard universal sighted/human guide. But then, within these sub-communities, each blind person and their friends or partners or family come up with their own shared signals.

Nas Campanella

Yeah, absolutely. And I think it's in the same way that people would come up with their own sort of ways of, you know, eye contact and all kinds of things. It is just like anyone, any kind of community would come up with their own sort of way of, of communicating, which I think is, is really great.

Haben Girma

This is actually, one of the things I miss the most during the pandemic is Protactile and meeting people and connecting with people. I used to go swing dancing about every week, and it’s a way to connect with people, and express joy and build community. And for others, it's also enjoying music, but I'm not really listening to the music – just paying attention to the dance.

Nas Campanella

Talk me through a dance class when you are Deafblind. How does it work?

Haben Girma

In my book, there's a chapter on my first salsa lesson. It was at a camp for the blind and it was actually taught by a blind dance instructor, which blew my mind. Nowadays, I'm like, of course blind people can dance. But back then when I was still learning, I was surprised. I know today there's still many people who are surprised. And the way she taught the class was through verbal descriptions, and touch. She would let me feel her feet, feel her movements, so I knew exactly what to do. And in partner dances like swing and salsa, people are in close contact, you're holding hands, you have an arm on his shoulder. And through that you can feel the movement and rhythm and beat. I'm actually not hearing the beat to the music. But… I can feel it through the hands and shoulders of the people I'm dancing with.

Nas Campanella

Look, I'm not going to pretend to be the world's greatest dancer, but I did some dance classes just before my husband and I were about to get married, and I think it is really funny that a lot of people were asking, “Would we do our first dance?”. I mean, of course we would! Just because I'm blind doesn't mean that we wouldn't do that. And I found it really strange because dance is all about movement. It's about how it feels. And so I guess I was quite confused as to why people wouldn't associate that with someone who was blind and you know, for someone who is deaf, you can obviously feel vibration of the music as well.

Haben Girma

What dance did you and your husband do?

Nas Campanella

We, our first dance was to Nat King Cole's L O V E. And it was quite a fast-paced sort of dance. Just very basic, you know, the one to, one two step back and forth. We did a bit of movement sort of up and down, I guess the dance floor, just in terms of a couple of twirls here and there. It was a lot of fun. A lot of fun.

Haben Girma

And do you two still dance?

Nas Campanella

Oh, not so much. But I did really enjoy it. I felt like it was just so lovely to feel the music and feel the movement. I think, with how busy our lives can get with work and rushing from one thing to another. It was nice for me, learning to dance was just being able to let loose and relax and feel whatever your body kind of wanted to do. And nothing ever felt wrong, I guess. Even though it might have looked a bit wrong. (Laughter) It just was a really lovely freeing experience.

Haben Girma

Yeah, I love the joy in movement. I dance in very inclusive communities. Experienced dancers are expected to dance with beginning dancers. And when I dance, I am just following, I'm connecting. And that means meeting each person where they are, where they are in their dance journey. They could be a beginner or advanced dancer. It's really about the connection, not about impressing the audience, or even about staying on beat. It's about the connection.

Nas Campanella

And look dancing is just one thing in my life where I've had people assume that I couldn't or wouldn't do that. And it's all based on people's assumptions and attitudes of what people living with a disability can and can't do, or what they should and shouldn't do. How do we change those attitudes Haben?

Haben Girma

You change them by – keep dancing, Nas! Every time you and your husband dance, you're changing the world. Every time you go off to a dance party or an event and you dance, you're changing the world. When we put positive disabled stories out there, even if they are our own stories, we're asking people to change their negative assumptions and adopt a new disability worldview. And this story, this interview you're producing is also going to be one of those changes.

Nas Campanella

Haben, you have a guide dog called Mylo. Can you tell us about him?

Haben Girma

Mylo's amazing! Wonderful Seeing Eye dog. We trained maybe just less than two years ago, the summer of 2018. And he was trained at The Seeing Eye in Morristown, New Jersey. It's quite a process to train with the dogs. He was trained to guide, but with his instructor. When I came into the guide dog school, I was just some random person to him, and he felt no responsibility toward me. So, it took time to build up a relationship to build up trust. Just like it takes time with humans. When you're building a relationship with a human, you have to establish boundaries, learn to communicate with each other. He's my second guide dog. I had to get rid of all my expectations from my first guide dog and stop comparing him to precious Maxine and see him for who he was, for Mylo.

Nas Campanella

A lot of guide dogs here in Australia are either Labradors, Golden Retrievers, or I think Labradoodles as well. Mylo is a German Shepherd.

Haben Girma

That's right and it's very intentional! Labs and Goldens are also really common in the United States. The guide dog school near me in California mostly does Labs and Goldens and I think mixes of the two. I wanted a German Shepherd. German Shepherds have amazing pointy ears, very expressive, very adorable. They're also extremely intelligent and loyal. So, I researched all the different guide dog schools. What are the hours of training the dogs go through? How, how well is the training process? And I found The Seeing Eye. It's the oldest guide dog school in the world. And I applied to go there, trained there with my first dog, Maxine, who was also a German Shepherd. Then in 2018, she passed away due to cancer and I went to the Seeing Eye again and trained with Mylo.

Nas Campanella

Haben you have used a cane, or I assume you still do sometimes. I use a cane and I am thinking about getting a guide dog. Sell it to me, why would I? Why would it be beneficial to get a guide dog?

Haben Girma

It's a personal choice. The cane is fantastic. But the cane, you don't have to feed it. It doesn't need to pee. When you're done traveling, you could put it under your chair along the wall or even fold it up and put it in your purse. But the guide dog is always there. And the guide dog has so many needs. It's a huge responsibility. So, it's very much a lifestyle choice. You have to be ready to have all the responsibilities. I love the lifestyle. Travelling is so much easier with a guide dog. With the cane, you have to bump into every single obstacle in your path. Not you specifically but the cane. The cane taps an obstacle, then you know it's there and you move past it. Whereas with the dog, it'll zip right by the obstacle. So, it's more efficient, faster. And it just feels more fun to me to travel with a guide dog.

Nas Campanella

My friend Rachel who follows you on Instagram would be very upset if I didn't ask. How does Mylo rest? What does he like to do to rest?

Haben Girma

Mylo has lots of toys at home. So, he will play with his various toys. He has a stuffed toy whale that he likes to hold in his mouth and snuggle. And then every day, we take him to a park where he runs and chases a ball. We play fetch with a chuckit, so I throw the ball with a chuckit he runs after it catches the ball and brings it back. He gets lots of opportunities to run. And now during the pandemic, I'm walking every day about three miles. He is going on walks all over.

Nas Campanella

Haben, what does success look like to you? How would you describe success?

Haben Girma

Success is finding your purpose and developing the skills to fulfill your purpose. All of us need to find a way to give back to our communities. We all have unique skills and talents that will benefit our communities. It takes time to figure out what that is. It took me a while to figure out mine. After experiencing lots of barriers growing up. And in college, I realised the power of using the Americans with Disabilities Act and advocacy to remove barriers. And I wanted to turn that into a career and advocate for people with disabilities. So, success is finding your strengths and tapping into those strengths to give back to your community.

Nas Campanella

Haben, looking into the future technologies. I guess, is the same way it is for me for you a very big part of your life. And we have such a long way to go even though we've got amazing bits of technology that have been developed to allow us to do what we do. What is one piece of technology that you would like to see in the future?

Haben Girma

I would love to see accurate and dynamic speech to text technology. There is already some tech out there that'll do that, but it's not accurate or reliable and dynamic settings. So, I'm excited for that to improve over the years.

Nas Campanella

I think something that I have found quite frustrating as technology has advanced, it's also gotten in some circumstances, less accessible. So, for example, our coffee machine has broken down. And we were looking for a new one and they are all touchscreen. I need tactile buttons. Are you experiencing similar things?

Haben Girma

Oh, yes, absolutely. Fight back on those coffee machines! Coffee is important. You need coffee to do your job. Tell them to get an accessible version of those coffee machines.

Nas Campanella

Haben, do you often, do you ever get advocacy fatigue? And how do you deal with it when you do? Because it can be incredibly exhausting to continuously fight for equity.

Haben Girma

Oh, no, it's part of their strategy! They think by taking away your coffee, you'll stop advocating.

Nas Campanella

(Laughter). I hope not.

Haben Girma

(Laughter). Because if we don't have our coffee and food, advocacy fatigue sets in a lot faster. We do need to have our basics met before we have the energy to advocate. And that's why it helps to have a community. If you can't advocate for yourself, your community can step in and help advocate for you.

Nas Campanella

Haben, what do you want to be your legacy?

Haben Girma

(Laughter). Well, my book for one, I wrote the book to help teach people to advocate. It helps people recognise what is ableism? How does it intersect with sexism or racism, or all the different struggles in the world? So by making people aware, it'll help move people to start addressing it and removing it from our communities. So, I hope my book will help teach people to be advocates for inclusion.

Nas Campanella

Haben, this conversation has been so fascinating. And it's been an absolute pleasure to talk to you to learn from you. And I thank you for everything you do for our community and for everything you are teaching the nondisabled community as well. Thank you so much.

Haben Girma

You're so welcome, Nas. And if you want ideas for how to fight for your coffee, let me know.

Nas Campanella

I will keep that in mind. As you say coffee is way too important.

Haben Girma

Exactly. I'm from, my families from Ethiopia – where coffee started.

Nas Campanella

Exactly. So that's, yep, you have firsthand experience of how important that is. Haben, thank you so much for your time.

Haben Girma

You're welcome, and thanks for your time, Nas.

This podcast is presented by the UNSW Centre for Ideas in partnership with the UNSW Disability Innovation Institute. Supported by the Auckland Writers Festival.