

Theresa Stern: Welcome to Central Bark, a podcast from Guide Dogs for the Blind. I'm Theresa Stern, and I'm your host.

Hello, everyone, and welcome to Central Bark. We have a very special episode today. We are speaking with Dr. Arielle Silverman, who works for the American Foundation for the Blind. And GDB and the American Foundation for the Blind partnered on a two year research project looking into the future of guide dog use in the United States and Canada. So today I'm so excited to welcome Arielle. Welcome, Arielle.

Dr. Arielle Sil...: Thank you so much, Theresa.

Theresa Stern: So Arielle, tell us a little bit about your background and about what you do at AFB.

Dr. Arielle Sil...: Absolutely. So I have a doctorate in social psychology from the University of Colorado Boulder. I received that eight years ago. So I've always had an interest in kind of science and research and learning about human behavior. And I've also been blind since birth. So I've always been passionate about using research and data to make lives better for blind people and people with low vision by understanding some of the barriers or some of the factors in the environment that can create challenges for blind people and people with low vision and figuring out solutions to those barriers.

So after I completed my doctoral training, I did a post doctoral fellowship at the University of Washington and I learned some different methodologies and learned about different types of disabilities and things like that. For five years I was self-employed as a consultant, working with different organizations to help them with their research. And I also did some disability awareness and inclusion training. And then in January of 2021, I started working with the American Foundation for the Blind first as a consultant assisting with some of their research, including the work that we'll talk about today. And then I joined the AFB team full-time as a research specialist in September of 2021 and became the director of research in April of 2022. So I joined the team kind of in the middle of the collaboration with GDB.

Theresa Stern: That's great. It's been great having you on this project. I think it's especially helpful that you're visually impaired too. You kind of get all the nuances that come along with this. And so it's been really fun working with you on this. One of the reasons that Guide Dogs for the Blind decided to do this type of research is because there's very little in the field about guide dogs. There's very little research about blindness or guide dogs and very, very, very little, little, little about guide dogs, if we could say it that way. But I think it was really important for us at Guide Dogs for the Blind to make sure that our services remain relevant as we move forward into the future. So this was really important research for us. And we also felt like this is research that could be shared industry-wide, so with other agencies who serve people visually impaired and especially with

other guide dog programs. So again, it's been really fun working with you on this. So Arielle, can you tell us a little bit about the design of the study and who participated?

Dr. Arielle Sil...: Yeah, so we wanted to do a mixed method study, meaning that part of it was getting statistics from folks and part of it was getting more open-ended responses to questions and learning more about people's stories with guide dogs and travel. First of all, we went and reviewed the literature to learn what other researchers had done and what they had found about guide dogs. And we found that there was indeed not a whole lot of research about guide dogs, and it was hard even to identify a prevalence estimate for the percentage of folks who use guide dogs in the US. After that, we did a survey, so we had 533 individuals and about half of them were guide dog users and the other half were not, but all blind and low vision individuals complete a survey. So we were able to get some statistical information that way.

And then after that we interviewed some folks and we started out by interviewing GDB clients and staff to really drill down into some questions about what GDB does well and maybe areas that GDP could improve on, and learning more in depth about people's experiences going through GDB's programs and some of the ways that GDP staff kind of adapt to challenges or what kind of their outlook on guide dog use. We started with GDP folks and then we expanded and did interviews and focus groups with guide dog users from other schools, staff from other schools, and particularly guide dog users from different groups. So people who were young adults who had just gotten their first dog, people who were older adults who had had like up to 11 guide dogs in their lives, people with additional disabilities, people who identified as people of color. We also included six O&M instructors to get their perspective.

And at one point we said, "Well, why are we just talking to guide dog users? If we really want to understand the landscape, we need to also talk to people who have decided not to use guide dogs." And we had some of that from the survey, but we wanted to get more in depth look at their experiences. So we included eight people who did not use a guide dog who use a cane. We also included two people who did not use a guide dog or a cane. There were people with low vision who did not use mobility aids at all. So it really gave us a very broad cross section of the community and we were able to understand multiple perspectives on some of these issues.

Theresa Stern: Yeah, definitely. And I think one of the things that surprised me the most, which is probably because I'm not sort of a techy person, but was kind of in the area where we were looking at trends of people who are traveling now. And I believe you found that most people who work with a guide dog are also using some sort of technology along with their guide dog or with their cane to sort of navigate their world. Can you talk a little bit about that finding?

Dr. Arielle Sil...: Yeah, so on the survey when we asked people what tools they use during travel, one of the options that they could select was that they use a smartphone. And about three quarters of the respondents indicated that they use a smartphone during travel. And that was about the same for the guide dog users and the non guide dog users who were surveyed. And of course some of those folks probably just said that they use a smartphone because they have it with them and maybe they listen to music on the train or something like that.

But in the interviews, most of the respondents did indicate that they use smartphone apps specifically to assist with travel. And we dug a little deeper and we asked what apps do you use and how do you use those apps? And the responses I think fell into two main categories. So a lot of people said they use like GPS way finding apps, and those could be either mainstream apps like Apple Maps or Google Maps, or it could be blindness apps like Nearby Explorer or BlindSquare or Soundscapes, which is one that I had actually not heard of that I might want to try.

Theresa Stern: Yeah, it's pretty cool. I've tried that one.

Dr. Arielle Sil...: The Soundscapes came up multiple times. So they said they use it for route planning ahead of time and also turn by turn navigation while they're traveling. The second group of apps were visual interpreting apps, which of course are fairly recent. So things like Be My Eyes and Aira. And of course those apps cannot replace a cane or a guide dog, but they were often cited as providing kind of supplemental support, particularly if someone got turned around and they needed help navigating back on course, or if they were going to an unfamiliar place and they needed to find like the specific room in a building, for example. They found visual interpreting apps to be really helpful for that.

Theresa Stern: Arielle, for those our listeners who maybe not have had much experience with apps for folks with visual impairment, those new interpretive services are really kind of different. Can you explain to our listeners how that works?

Dr. Arielle Sil...: Sure. So these are apps where you essentially, it's like a FaceTime call. It's like a video call with someone on the other end who is sighted who can see whatever's in the camera view and provide support. In the case of Aira, they actually have professionally trained agents that they hire and pay to provide the service. And in the case of Be My Eyes, it's volunteers around the world who provide the service. And so people can call in and they can ask questions. So for example, it might be aiming their camera looking for a sign in a building to find the specific suite number that they need. It could be looking as they're walking down the street to be able to find a specific landmark that might not be obvious non visually. And in the case of Aira, at least, they can also help with online resources. So you could call and say, "Can you look on the map and tell me what restaurants are around me," for example. And Aira provides a GPS point to the agent so they can tell exactly where the user is and can provide feedback that's requested.

Theresa Stern: Very cool. Very cool. Do they do your homework if you're in high school? No, just kidding.

Dr. Arielle Sil...: Probably depends on what agent you get.

Theresa Stern: I know. If they got me I wouldn't be able to do the math, that's for sure. Another trend that kind of came up, I think during this survey, and it's kind of interesting that our survey happened to sort of fall around the time of the pandemic, but it does seem like a lot of the respondents were saying that their travel has sort of changed over the years and probably especially with the pandemic. Can you talk a little bit about that and then a little bit about the double-edged sword of rideshares?

Dr. Arielle Sil...: Sure. So regarding the pandemic, there was a pattern of people talking about, which we all know, workplaces went remote, so people weren't necessarily having a regular routine of going out and going to work in the office. And now it's kind of a hodgepodge in terms of some workplaces still being remote, some workplaces being hybrid or partially in person, and then some being fully back in person. But overall, people weren't going out as much because we were doing these interviews when the pandemic was still in full force and vaccines were just barely starting up. And so people definitely reported a reduction in their activity levels. But there was also a pattern of people talking about maybe not walking a lot of places because rideshare is really convenient way to get from one place to another directly without having to stop and wait for a bus and those kind of inconveniences.

So people commented on the fact that they didn't necessarily walk a lot of places because they were going door to door in a car. And sometimes the guide dog users would say they had to build into their routine walking opportunities for the dog. So the dog still got work. It was more of a challenge for some folks and for others depending on where they lived and what was available in the neighborhood and how walkable their neighborhood was. And rideshare, of course, provides a lot of convenience but also creates a barrier in a lot of cases for guide dog users because of the high rate of service denials with rideshare drivers. They see the dog and then they just cancel the ride or they come up with some reason.

And sometimes even, it didn't come up in this study so much, but I've heard just among my friends, that in the wake of COVID that drivers will even lie and say that the person is not wearing their mask in order to get away with not taking them with their dog, which is terrible and then it ends up negatively impacting the rider, of course. And so this came up repeatedly. So for example, when we ask questions about are there any places you would not take your dog to, people would say, "Well, if I'm in a huge hurry and I need to get to an appointment on time, I might hesitate to take my dog because I'm afraid that like Uber or Lyft is not going to take me."

Theresa Stern: That's so frustrating.

Dr. Arielle Sil...: It also came up of course in terms of advocacy challenges, having to advocate with the drivers. And then on the flip side, people who didn't have dogs would say, "Well, I don't want to deal with that. I use Lyft and Uber all the time. I don't want to have to worry about them possibly denying me because I have a dog." So that was a deterrent from getting a dog for some folks.

Theresa Stern: Wow. That's so crazy. Something that really could be super helpful in terms of inclusion also being sort a deterrent to really personal choice as to how you want to get around in the world. That's a little distressing. So tell us about what surprised you or what sort of hit you when you asked people why they chose to have a guide dog, to work with a guide dog.

Dr. Arielle Sil...: So I don't know if it necessarily surprised me because I know a lot of guide dog users. I'm actually one of the people who chose not to use a guide dog, but I have a lot of friends and colleagues who do, and they've talked about the practical benefits as well as the emotional benefits of having a dog. I think what maybe is interesting, I guess not really surprising, but it's interesting, is socially the guide dog can be also a double-edged sword.

So some people said that having a dog made social interactions smoother and people were more likely to approach them and be more positive, whereas if they had a cane, people would distance themselves or be kind of fearful of the cane or they would have a different stereotype about cane users not being very independent. But if they had a dog, they felt like people viewed them as a lot more positively.

Then on the other side though, there are a lot of challenges, particularly with people like interfering with the guide dog in different ways, like petting or feeding or talking to the dog. Of course, even when they say, "You know, you can't do that, please don't do that," people would persist at it. Some people talked about family and friends didn't quite get it, like how the dog worked. For example, they would continue to try guide, like they would get upset if it looked like the person was about to run into something and the person would be like, "No, my dog can see it and will take me around it." Their family didn't always understand that.

Theresa Stern: That makes sense.

Dr. Arielle Sil...: So socially and interpersonally, the guide dog can be great, but it can also present some unique challenges.

Theresa Stern: Yeah, absolutely. As a guide dog user myself, I can say yes indeed to all of the above. Oh my goodness. So I know you talked to some people who weren't using guide dogs and was there any barriers there that you felt like were kind of

sort misconceptions about guide dogs that maybe we can bridge those gaps for folks?

Dr. Arielle Sil...: So there were some folks who indicated that they believed that people with a lot of residual vision either wouldn't be allowed to get a dog or they wouldn't benefit, or that they were taking a dog away from someone who was totally blind, who was perceived as being more deserving or more needy perhaps. And there's definitely some truth to the fact that you have to meet certain criteria vision-wise in order to qualify to get a guide dog, but there's not necessarily the shortage or rationing of guide dogs that some people might perceive there to be. And people who had low vision definitely indicated that having a guide dog, as long as they were legally blind, having a guide dog was still helpful and increased their independence and freedom and confidence.

So I think that that's definitely a misconception that can be addressed is understanding that even if you have significant usable vision, as long as you know how to balance that with trusting the dog and working with a dog appropriately, that can still be beneficial. I guess the other thing that is just maybe concerning is the shortage of O&M services was frequently cited as a barrier or reason why people either self-selected out of getting a guide dog or were denied.

Theresa Stern: Ah, okay, yes.

Dr. Arielle Sil...: Because they didn't have the O&M. And I mean, that's something that definitely intervention needs to be introduced to provide more O&M services to more folks, not just so they can get guide dogs, but so they can just have all the tools available to them to be more independent.

Theresa Stern: Yeah, absolutely. I mean, there's really a dearth of that service for folks and it seems like it's getting worse. So I know here at Guide Dogs for the Blind, we are providing an orientation mobility immersion program for that very reason. So we'll have to do another Central Bark about that, I think.

Dr. Arielle Sil...: And then finally I would say just, and we talked about this earlier, but the fact that people often just weren't doing enough walking to justify having a guide dog is also interesting. And some folks said that they'd had a guide dog and they wanted to have another one, but they couldn't because they lived in a place that wasn't conducive to a lot of walking.

Theresa Stern: And I think a lot of the way that new communities are being built, they're built more for vehicles than pedestrians. So I can see that kind of being a barrier as well. Yeah, very good. So this, Arielle, it sounds like you and I are going to be hitting the road soon to share what we've learned on this. Can you tell us a little bit about what's coming up for our partnership?

Dr. Arielle Sil...: Absolutely. So we have been accepted to present at the International Guide Dog Federation Conference in Vancouver next April. So I'm super excited about that. It'll be a lot of fun. We're also hoping to submit a proposal to speak at the California Transcribers and Educators of the Blind and Visually Impaired Annual Conference. So that will help us reach out to particularly the O&M community to help them understand maybe some of the ways that orientation and mobility and guide dog professionals can collaborate more and be sure that young people have the information that they need to be able to decide if a guide dog is the right tool for them.

Theresa Stern: Right. And then I think we're doing a couple articles as well, so again, we're just really going to try to get that word out. So Arielle, did the study illuminate any particular communities that are really underrepresented as guide dog users?

Dr. Arielle Sil...: Yeah. First of all, cultural minorities or certain cultural groups can sometimes face barriers related to cultural attitudes about dogs generally and about guide dogs in particular. So for example, we had some participants from Latino, Latina backgrounds and they spoke about as part of their culture, really emphasizing family interconnectedness and interdependence. And so there was often just a conception that family members would help each other and why would you need an animal to help you because you have family to support you. And they said like there's a shortage of guide dog materials in Spanish, but even with materials in Spanish, it's important to help educate those communities about why a guide dog could be beneficial.

Of course, there's also other cultures where having a dog in the home is not considered appropriate depending on certain beliefs about dogs in the culture. And so people might have difficulty getting their family to accept a dog in the home. And so it's important for guide dog schools to be aware of those factors.

The other group that we spent a lot of time really looking at is people with additional disabilities. And in the survey we found that about one fourth of the respondents said that they have some sort of chronic health condition and then it was about 10% each for hearing impairments, physical impairments, and mental health disabilities. I mean, I guess the good news is that those conditions were about as common for guide dog users as for non guide dog users. So guide dog users with multiple disabilities aren't necessarily being excluded from the opportunity to get a guide dog.

But when we talked with GDP staff, it was clear that GDP staff really make an effort to individualize instruction and accommodate people with various types of disabilities. But we also talked to some folks who were not aware that GDB provides those services. So some schools have a reputation for being especially good for deaf-blind people or people with certain types of disabilities. And so if GDB wants to stay ahead of that curve, we made some recommendations about how to be more explicit in outreach and recruiting to be clear that those services are provided.

There was also feedback about just being sure that folks are more aware of mental health disabilities and some of the mental health impacts of things that could happen with a guide dog, like if the dog gets sick or retires or there's a match that doesn't work out. And sometimes even just like the overwhelm of going through training could be hard for people with mental health disabilities, but they can do it if they have the right support.

Theresa Stern: That's right. That's right. That's such great information we got from this study and I'm so excited to get this information out to the world so that we can all provide better services for people who are blind or low vision and really let people know what their options are in terms of getting around independently and with confidence. And I've really appreciated having you here today, Arielle, and I look forward to working with you some more on this project.

Dr. Arielle Sil...: I do too. Thanks so much.

Theresa Stern: For more information about Guide Dogs for the Blind, please visit [guidedogs.com](http://guidedogs.com).