**Flatten Inaccessibility: Using Data to Ensure COVID-19 Responses Are Inclusive of Adults with Vision Loss – Virtual AFB Leadership Conference 2020 – Complete Transcript**

**Part I: Presentation**

**Text on screen:**

AFB Virtual Leadership Conference 2020. Connecting Online. Flatten Inaccessibility: Using Data to Ensure COVID-19 Responses Are Inclusive of Adults with Vision Loss.

L. Penny Rosenblum, Ph.D. American Foundation for the Blind, Director of Research;

Paola Chanes-Mora, M.P.H., Ph.D., CHES, American Foundation for the Blind, Policy Research Specialist;

Troy Otillio, Aira, Chief Executive Officer;

Bonnielin Swenor, M.P.H., Ph.D.\_x005F\_x000B\_Wilmer Eye Institute, Johns Hopkins University, Associate Professor.

More Resources for You: AFB.org/VirtualAFBLC.

**Narrator:**

Thank you for connecting online with us for the AFB Virtual Leadership Conference 2020, and this session titled "Flatten Inaccessibility." Now, a welcome message from Kirk Adams, Ph.D., President and CEO, AFB, and Roslyn Adams, Spouse and AFB Ambassador.

**On screen:**

Dr. Adams, a man with salt-and-pepper hair, and wearing a business suit, sits next to Ms. Adams, a woman with dark wavy hair, and wearing a bright purple blouse.

**Dr. Adams:**

Hello, I am Kirk Adams. I am President and CEO of the American Foundation for the Blind.

**Mrs. Adams:**

My name is Ros Adams, I’m married to Kirk and I’m a longtime supporter of AFB.

**Dr. Adams:**

And we thank you all for joining us from your living rooms and home offices across the country. We are in our apartment here in Arlington, Virginia, and we welcome you to our Virtual AFB Leadership Conference. Now our Leadership Conference is really the highlight of our year, we bring hundreds of people together, all dedicated, passionate individuals, who are all committed to creating a world of no limits for people who are blind. This year, for obvious reasons, we’re bringing you our conference virtually.

**Mrs. Adams:**

We’re really excited that you’re joining us, and as an educator I’m particularly happy about the fact that we’re using technology to help us stay connected at this time.

**Dr. Adams:**

We wouldn’t be able to present you with this virtual conference without the help of our supporters and partners and friends. I want to thank Bridge Multimedia for lending a hand in creating this virtual content, and our sponsors who make it possible for us to provide this content free of charge for anyone who could find it useful. Please do share!

**Mrs. Adams:**

So I just want to stress that this is our opportunity to continue to learn from each other. So do enjoy the session and please take the time to visit us online at AFB.org/VirtualAFBLC.

**On screen:**

A photo shows a woman, with dark glasses, working on a desktop computer in a home office.

**Text on screen:**

Flatten Inaccessibility: Using Data to Ensure COVID-19 Responses Are Inclusive of Adults with Vision Loss.

**Logo:**

AFB - No Limits.

**Text on screen:**

Meet the Presenters:

L. Penny Rosenblum, Ph.D. American Foundation for the Blind, Director of Research;

Paola Chanes-Mora, M.P.H., Ph.D., CHES, American Foundation for the Blind, Policy Research Specialist;

Troy Otillio, Aira, Chief Executive Officer;

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**On screen:**

A man with short silver hair speaks to us, remotely:

**Troy:**

Hello, everyone. My name is Troy Otillio. I am the Chief Executive Officer at Aira.

**On screen:**

A woman with short hair and glasses speaks to us remotely:

**Penny:**

Hello, my name is Dr. Penny Rosenblum. I'm the Director of Research at the American Foundation for the Blind.

**On screen:**

A woman with long brown hair and glasses speaks to us, remotely:

**Paola:**

Hi, I'm Dr. Paola Chanes-Mora. I am at the American Foundation for the Blind and I am a Policy Research Specialist.

**On screen:**

A woman with long light hair speaks to us, remotely:

**Bonnie:**

I am Dr. Bonnielin Swenor. I am an epidemiologist and Associate Professor at the Wilmer Eye Institute at Johns Hopkins University.

**Troy:**

Welcome to the session titled *Flatten Inaccessibility: Using Data to Ensure COVID-19 Responses Are Inclusive of Adults with Vision Loss*. So, I'm going to introduce how we got started. Where did this idea come from? What led up to this talk today?

And the idea was pretty simple: we wanted to find out as a large working group, how has COVID-19 pandemic impacted the lives of adults with vision loss in the United States? And as you can see, this resulted in a website and even a fancy logo.

**Logo:**

A logo labeled "Flatten Inaccessibility" shows an illustration of a person near a sharp curve and a flattened curve.

**Text on screen:**

https://flatteninaccessibility.com/.

**Troy:**

But I think what's interesting to start is to talk about kind of the timelines and the themes leading up to it. So I'm going to talk about that. I'm going to share how it got started, how we got organized because I think that's exciting to see the industry come together. And then I'm going to turn it over to the really smart people in the room to describe what we found in the results so far and what we're going to do next.

So as you can see, this all started around March. In fact, I find that CSUN was kind of instrumental in the lead-up here. I personally went to CSUN, I know a lot of people planned to go to CSUN and they didn't. And what we found, or what I discovered, is there was about half the participants, but four times the conversations, because of course COVID was gaining momentum and nobody knew what it would mean. And at the same time Aira is this connected service, where we got thousands of users talking and working with our agents everydayand we were seeing a change in behavior in the task pattern and the call pattern. And we also have online communities and we were seeing people reach out and talk to each other about their concerns. So we decided we needed to know more.

And within Aira, we launched a survey within about a week and we were surprised 'cause it was hastily launched, it was a long survey. And lo and behold, we got 240 responses, some of them talking about the user's concerns about like tactile tasks, their health, and remote accessibility. And in response, Aira launched a distance learning offer and engaged employers and universities to deploy Aira as one accommodation in this changing scenario.

And so that led to the thought of, well gee, shouldn't the industry come together and shouldn't we as a group collect more information and partner on next steps? And so with that, myself and a few others floated the idea amongst each other. And it was around March 23rd that I think the, the idea became solid. Like, yes, we should launch a broad survey to collect more data. And within 10 days, which I think is very rapid, we had a working group of 16. And that working group included the companies and the organizations that you may have already seen that I'll describe later to come together and both produce the survey content. Like what questions should we ask, what topics, what areas should we cover, to set up a website so that we can facilitate the distribution of the survey, and then communication, like using the channels and the communication mechanisms of all the different companies and organizations to reach as many people as possible.

And that survey launched on April 3rd, which was roughly 10, 15 days since we formedand the survey closed on the 13th of April.

**Text on screen:**

Timeline and Themes:

* April
  + 3rd: Survey launch (11 days since formation!)
  + 13th: Survey closes.
* May
  + 4-15: Five installments summarizing the data posted.
  + Current: Full report under development.
* June 4th: AFBVLC Flattening Inaccessibility Webinar

**Troy:**

And since then, the team has been working very hard. I know 'cause it's a lot of late nights and weekends compiling the information, there's already some installments out on the website with some early findings. And currently that, you know, the group who's focused on the data is under full report development and, and should be finishing.

And when, when I look back on what happened, there's some key themes here. One is we as a group, I don't want to say struggle, but we, there was some question about how fast should we move versus the quality and the brevity. There's a real challenge in developing a survey that is quick but also is comprehensive. And when you bring together a lot of different folks with basically different contexts, you're going to get a lot of different opinions. And at the same time, COVID’s going on and it's affecting all of our organizations, so there's a lot of distraction, right? Like this wasn't anybody’s number one priority as an organization, but each organization did contribute people.

And I think the final takeaway I had that I was pretty excited about, 'cause we read about it a lot about the, the benefit of diversity. And I would say that we were all pleased that by bringing in more groups into this organization, we got a broader perspective of what topics and what concerns might be out in the community. We went from maybe three or four high-level topics to seven within two or three days and I thought that was really an awesome outcome. So with that, I just wanted to share 'cause I think it's really important, the initial working group that was formed.

The organizations that participated here are both for-profit and nonprofit organizations and they start with the American Council of the Blind, Association for Education and Rehabilitation of the Blind and Visually Impaired, The American Foundation for the Blind, Aira Tech Corp., APH or American Printing House for the Blind, Be My Eyes, Council Schools and Services for the Blind, HumanWare, the Johns Hopkins Wilmer Eye Institute, The Professional Development and Research Institute on Blindness at Louisiana Tech, National Federation of the Blind, National Organization for Albinism and Hypopigmentation, Prevent Blindness, VisionServe Alliance, and last but not least Vispero.

So I think that's an awesome set of folks and there's yet another 20 have requested to participate. So there's a lot of energy and interest from the broader community of those who support or work with the community of the blind or low vision. So that's a little bit of the background, I hope that gave the context and the setup for what is really the meat of this presentation. Next, we'll hear from Dr. Rosenblum about the survey design.

**Penny:**

So as Troy mentioned, putting the survey together was a collaborative effor, we did in a very short period of time. I'd like to share with you that the survey is fully accessible with NVDA, with JAWS, and with VoiceOver. And we really thank the folks at Aira, AFB, and Vispero who went through painstakingly to make sure that the survey is accessible. We had no complaints about that.

The survey actually contains 11 sections. The first is a Demographics section followed by a Technology section, and those are required of all participants. After that, participants have a choice in what sections they wish to answer. We have sections on Healthcare, Transportation, Employment, Your Education, Your K-12 Child's Education, Your Social Experiences, Meals, Food and Supplies, Voting, and then just a couple final questions.

I’d like to tell you about the teams that are working on the data analysis. And this truly takes hundreds of hours to do. I’d like to introduce you to the quantitative data analysis team. It's led by Dr. Paola Chanes-Mora from AFB, Dr. Bonnie Swenor from Johns Hopkins Wilmer Eye Institute, Dr. Niranjani Nagarajan from Johns Hopkins Wilmer Eye Institute, Mr. Rett McBride who is a doctoral student at the University of Georgia, Joshua Flewellen from Aira, and Dr. Jonathan Noel from the University of Connecticut. And these folks are working hard to look at the data by different groups such as by age or geographic part of the country.

The qualitative team is led by myself, Dr. Penny Rosenblum from AFB. Cynthia Bennett is representing the National Federation of the Blind. Rosemary Nave Stawasz is a volunteer who's currently employed at the Hines VA. And Dr. Bonnie O’Day, is the past Interim Director of AFB's Research and is volunteering her time as well. I’d like to turn it over to Dr. Chanes-Mora, who's going to talk to you about the Participant Demographics.

**Paola:**

Thank you, Penny. Our total sample population for the survey ended up being 1,921 participants. Our total sample did represent all 50 States, including the District of Columbia and Puerto Rico. About 60% of participants were congenitally visually impaired, which means they were visually impaired prior to the age of two. 63% of participants were female, 35% were male, and the remaining percent identified as transgender, gender nonconforming, or other. 42% of participants also reported having an additional disability. The three most frequently reported disabilities, other disabilities, were diabetes, hearing impairment, and significant psychiatric disorders. 75% of participants were white, 7% were Hispanic or of Hispanic origin, 7% were black or African American, 4% multi-racial, 3% Asian. 44% of participants were also 55 and older.

It is important to take into consideration the demographics of our sample population as I continue to share the results of the study. As I just described, our participants were primarily female, predominantly white, and were older in age. The Flatten Inaccessibilitysurvey provides a roadmap to the COVID-19 response for people with vision loss. Even though it may not completely represent the general blind or visually impaired U.S. population, these data do provide great insight into concerns individuals who are blind or visually impaired are experiencing through the COVID-19 pandemic.

The first section that I will be reporting is in technology. It's really important to take into consideration as well that the survey was done online, so participants must already be somewhat savvy in terms of technology. So throughout the survey, statements were provided to participants and they were asked to select their level of agreement using ratings: strongly disagree, disagree, neither agree or disagree, agree or strongly agree.

What we did with the reporting of the participants, how they ranked their statements from strongly disagree to strongly agree, we give them a value and then we did the average, or the mean of each statement. So, a mean close to one tells us that most participants strongly disagreed with the concern and a mean close to 5 tells us that most participants strongly agreed with the concern. So the closer to three, the more neutral the participants felt regarding that statement. So for this statement: ***I am concerned the visual information about the COVID-19 pandemic is being shown on television and that this information is not accessible to me.*** The mean score was 3.51. That means that the sentiment was pretty close to neutral, or only slightly agreed by most participants.

The second statement was: ***As a result of COVID-19 pandemic, I have increased my use of apps designed to connect people with visual impairments with sighted assistance. For example, using Aira or Be My Eyes.*** The mean score for the statement was 2.7, so that means it was leaning towards disagree. So this indicates that most participants did not have an increase in use of apps designed to connect people with visual impairments with those with sighted systems.

Again, it's really important to take into consideration that this was an online survey. So it may not necessarily represent all of the low vision and blind individuals in the U.S. as inherently individuals to be able to navigate the survey must have used a computer. And only about 10% of the total participants needed help filling out the survey since that was an option that was provided to participants. And now Penny is going to illustrate some of our qual-- qualitative data.

**Penny:**

Thanks, Paola. So as Paola noted, the participants that took the survey really are primarily used to using technology, but COVID-19 may have had them have to learn how to use technology in different ways. So I have a quote for you - it's a little long - from one of our participants. "Technology has played a huge part; instead of face to face learning, I’m doing it online, which cuts out my need to commute on the city bus to school and back. My computer and iPhone cover the gap by allowing access to my classes. Zoom has allowed me to attend meetings that I would have had to travel to before the crisis. Aira has been my eyes, instead of using on campus resources for school-related activities such as purchasing books online. Finally I use my technology more to access information or services that I either use less or didn't use at all before the COVID[-19] crisis."

So for this individual, the number of technology tools listed are many. And so you can understand that part of what COVID has done for this individual has brought the ways that technology is used to a different level, more use of technology and using technology in different ways. Throughout the qualitative data, we hear over and over again participants talking about challenges with access. And the second quote I'm going to share with you illustrates that. "We need accessible healthcare mobile apps and websites. We need technology to represent graphical information in a format we can understand."

So many of our participants talked about that there is a lot of visual information about COVID-19 out there, from the maps that are shown on television to data tables on websites. And these aren't always accessible for them. Coupled with that are apps for online grocery shopping that are challenging many of our participants. So there are technology challenges out there that were recognized by the participants. Going to turn it back over to Paola to talk about healthcare concerns.

**Paola:**

Thank you Penny. So similarly to the Technology section, participants were also given statements and asked to rank how strongly they agreed or strongly disagreed. For the Healthcare Concerns, one of the statements was: ***I am concerned about touching things in public such as elevator panels, self-serve kiosk[s] or restroom doors to check signage.*** Most participants agreed with the statement. It had a mean score of 4.23. That means it was greater than agree; a lot of participants also strongly agreed.

The next statement was: ***I am concerned that if I am hospitalized with COVID-19 that I will not be allowed to have a caregiver with me who would normally assist me with accessibility issues in hospital settings.***This response was closely rated to neutral. It had a mean score of 3.68. However, it did also get close to most participants agreeing. So most participants had a slight agreement with the statement.

***I'm concerned about getting access to accurate and current information about those who may be infected in my area.***The mean score for the statement was 3.64. Again, it was either in, more than the neutral sentiment, but there was a slight agreement with this statement. So as we can see from this, these data, it indicates that most of the concern really relied around touching public signs in order to be able to reference and check signage. Not so much as long with assistance in a hospital setting. And now Penny will provide some insight with qualitative data.

**Penny:**

Overwhelmingly throughout the qualitative data, we heard many concerns related to COVID testing or getting care if one came down with COVID. This quote is representative of that theme: "I'm concerned about the prevalent policy decisions made thus far regarding using 'drive-thru' testing sites and various other curbside or drive through service delivery systems. I doubt I could get anyone willing to drive me or ask them to take on that responsibility if I were that ill. Leaves one feeling left out and forgotten."

Those sentiments are ones that came through loud and clear as we began to look at the qualitative data. That these drive-by testing centers, these dropping off somebody at the hospital and nobody being allowed to go with them, make people with visual impairments feel very vulnerable in a time where all of us are already feeling vulnerable.

A second quote I'd like to share with you has to do with eye care for many of our participants, a very integral part of their life. And like all folks who have been impacted by COVID-19, who doctor's offices are only doing tele-health or postponing appointments indefinitely, this is a concern. But when we're talking about eye care, especially for folks who have a progressive eye condition and need monitoring regularly, this really can impact their potential quality of life for the rest of their life.

Here's an illustrative quote: "I've waited almost a year to see an eye care specialist. And now my two-day appointment has been canceled in April and now I have to wait until September." So healthcare truly is a concern and coupled with healthcare, transportation really goes hand in hand. So I'm gonna turn it over to Paola to talk about some of those concerns.

**Paola:**

Thank you, Penny. Correct. When we look at the different mean scores throughout the entire survey and the different sections, transportation actually has the highest agreement with the statements. So we're, we're looking at means around 4 or higher than 4. So participants are asked these specific statements: ***Due to the COVID-19 pandemic, I do not feel safe taking public transit, taxis, or paratransit.*** Out of all of these three different methods of transportation, public transit had the highest mean score of 4.36. For taxis the mean score was 4.19, and for paratransit the mean score was 4.12. And again what all of these mean scores indicate is that participants strongly agreed with these statements, therefore showing us that there really are a lot of concerns regarding transportation within these three specific types or methods of transportation, public transit, taxis and paratransit. And out of all of these three, public transportation, which we defined as a bus or subways, had the highest concern.

Participants were also given two additional Concern statements. One of those statements was: ***I am concerned that because I do not drive, I will not be able to get myself or a family member to a hospital or healthcare facility if they have severe COVID-19 symptoms.*** The mean score for that statement was 4.18, which indicates the majority of participants did agree with the statement. Second statement was: ***I am concerned that due to the COVID-19 pandemic, my community has restricted or will soon restrict public transit, paratransit, taxis, and/or rideshare services such as Uber or Lyft.***And the mean score for the statement was also 4.17, very closely to the 4.18 of the previous statement. And again, it does indicate that participants had very strong concerns in comparison to the other sections of the survey regarding transportation. And now Penny will give us some quotes.

**Penny:**

Thank you, Paola. As a person with low vision, I am a non-driver. And though I'm fortunate to have a husband who is a driver, I truly can identify with many of the sentiments being shared by participants in this study when it comes to access to transportation. I worry for myself if something were to happen to my husband how I would manage my transportation during this difficult time. And we heard this over and over again from our participants. Let me share a quote with you: "Not driving is the reason we had to relocate during this pandemic. We don't trust the bus and having to touch everything on it and its limited services. Uber has been more costly. Access-A-Ride extremely limited their services...We talk every day about how disadvantaged we are not being able to drive."

For this individual and the people that this individual is living with, it's very clear that time has been spent weighing the different transportation options of paratransit - in this case, Access-A-Ride, buses, and, and Uber or Lyft, which we call rideshare services. We heard over and over again that even if the person felt safe using rideshare services or Uber, financially these were out of their financial resources with limited, limited resources even prior to COVID-19 or furloughs, or layoffs, or concerns about losing a job during COVID-19.

Another quote I'd like to share with you is: "I’m more concerned that rideshare and public transportation will be limited than I am that I will catch the virus while riding. Being cut off without the ability to get anywhere feels more immediately life threatening to me at this time." Many communities are reducing services or limiting the amount of services. Also some communities are requiring that people enter the bus from the back door. These changes, which are designed to protect the safety of those in the communities, are having extreme negative impact on many of the people taking the survey.

We heard through the qualitative data that for many having to enter the bus at the back door is problematic whether it's because you can't communicate with the driver, whether it's because you have an additional disability and accessing that step on that back door or those steps is difficult. So transportation truly is a concern for those who participated in this study. Going to turn it over to Paola to talk about Social Experience Concerns.

**Paola:**

Thank you, Penny. As we have seen throughout the theme of this presentation, Social Concerns also rated very, very highly in terms of the concerns the participants had in different sections. The statements provided for this section are as follows: ***I am concerned about asking someone to physically assist me with tasks such as grocery shopping or going to the medical appointments to practice social distancing.***The mean score for the statement was 4, indicating that most participants did agree with the statement.

The following statement was: ***I am concerned about asking someone to be my human guide in the community due to practice social distancing.*** Again, this one had a mean score of 4, also indicating that most participants agreed with the statement. The last statement was: ***Due to practicing social distancing, I am concerned about asking someone to touch my hands or allow me to touch their hands, for example, when using tactile sign language or being shown how to do something using hand-over-hand.*** The mean score was slightly lower than the previous two, but it was still very high. It was 3.97, indicating that there definitely was concern and agreement with the statement. And now Penny will provide some qualitative data.

**Penny:**

Thanks Paola. So when we think about the fact that we are social beings, that we don't tend to live in isolation. And yet visual impairment, as a general rule, is a social hindrance because we're not taking in, as a visually impaired person, a lot of that nonverbal communication. So therefore we need, we need touch, handshakes, and pats on the back to feel connected with people often.

Here's a quote that illustrates how this challenge of COVID-19 is impacting this individual socially. "I am an extroverted person by nature. The lack of human contact has been hard. I’m revitalized by other people. Having diminished auditory and physical contact has been incredibly jarring as touch and sound are incredibly important for feeling connected in blindness."

So this individual, like many others, was missing contact and some of our participants talked about how things like Zoom and FaceTime where friends and family, church groups are getting together does help. But that they, even in those environments, feel left out because they're not getting that physical contact, they're not getting those smiles that they're able to see. And though it's great to hear the people, it's not the same as being in the room with them.

Now, we all know that social distancing has become a huge part of our lives in the last couple months and that six-foot distance obviously is going to make it challenging with things such as human guide or hand-over-hand assistance. I want to share a quote with you that talks about the challenges of social distancing. "Social distancing has worsened my depression and anxiety, and the workload that has been piled on by switching to online classes and changing curriculum halfway through the semester, in addition to new responsibilities being added to my now remote job, has made me feel incredibly overwhelmed and incapable of surmounting the work I need to accomplish."

As this quote illustrates, the idea of social distancing, coupled with all the other stresses that people are experiencing during COVID-19, has led to a lot of depression, anxiety, loneliness, and fear for participants in this study. I want to have Paola talk about our last topic, which is also an area of concern for many, whether they do or do not have a visual impairment, but is exacerbated by having a visual impairment. And that's how do you access food, meals and supplies during COVID-19. So Paola, would you talk to us about those concerns?

**Paola:**

Great, thank you, Penny, yes. And this was also another section where participants described a lot of concern. I will read off now three of the statements that they were provided with. ***I am concerned because when I have tried to use an online shopping service, no delivery slots are available and/or the items I want are out of stock.***And the statement was also actually the second highest in agreement in this presentation with a mean score of 4.34, really representing that there was a lot of concerns for participants in terms of being able to access the items that they need and when they're asking for online shopping services.

The second statement: ***I am concerned that because of my visual impairment that I will have difficulty with the application process for SNAP or food stamps.*** And the mean score for the statement was 3.34, but it was definitely higher than a neutral sentiment, which would have been a score of 3. Therefore, it does indicate that participants are concerned about the potential application to the SNAP food stamp program.

The last statement: ***I am concerned that because of losing my job or having my hours reduced, I will not be able to afford the food and necessary supplies I need.*** The mean score for the statement was 3.27. Again, it also indicates that participants agree. And overall what the section illustrates to us is that there are several and pretty strong agreement with concerns regarding how individuals will be accessing food through the COVID pandemic. And now Penny will provide us with some qualitative quotes.

**Penny:**

Thank you, Paola. Though the numbers Paola just went over, the means were closer to three than they were to four or five, the qualitative data really speaks a different story. And that's why it's so important that when we're looking at survey data that we look both through, through the quantitative, the number piece, and the words piece, the qualitative piece, because over and over again we did hear about concerns.

So for example: "There are a number of food delivery services in my area. For several weeks I've been trying to get an available delivery slot, but to no avail." Regardless of what platform folks were using, whether it was Amazon, Walmart, through a local grocery store, we heard about the difficulty of getting a slot.

There were participants who recommended that online delivery services and stores have specific slots available for those with disabilities for the elderly, because those people who can get in their car and drive to the store who are choosing not to for safety still have an option. But those who don't have an alternative form of transportation, such as those with visual impairments who are non-drivers, are totally dependent on these services in many cases. So that was one concern.

Paola noted that we had participants who were concerned about SNAP or food stamps. One person shared: "Some delivery services are accessible, but not nearly enough of them and almost none of them accept SNAP."The idea that we have participants who are on limited income, who are dependent on SNAP or the food stamp program, and now are in a position where they need to first find an accessible platform to order food, and then they get that platform, they get in line, they put everything in their basket and they go to checkout to find out that they can't pay with their SNAP credits, is very disheartening and something that truly needs to be addressed from a policy level.

We also had participants who were in rural communities. And being rural and being a non-driver presents its normal challenges in a non-COVID pandemic situation. But you put COVID on top of this and these folks really are their own little islands without support. So for example: "We live 9 miles from the nearest town that has any kind of grocery shopping. They refused to deliver out here. Because we were supposed to stay at home, there's absolutely no way to get groceries. I've never seen so much price gouging in all my life. So the groceries are financially out of our reach as well and we are living on whatever is left in my pantry." You know, at some point this person is going to run out of food in their pantry. And where is that going to leave them and their family when it comes to the basic necessity that we take for granted, which is access to food in this country?

Another concern when we think about access to supplies and groceries is that many people with visual impairment have had strategies in place to get others to assist them with their shopping. Now with COVID-19 and the need to social distance, people are finding that others don't want to be near them because of safety concerns. "Wish the stores would deliver to my area. Right now if I order from them, I need to have someone drive in to receive items ordered. Neighbors won't do it due to COVID-19. So I'm required to order from Amazon; they don't always have the items that I need, so I go without."

As you have heard through Paola and my sharing, COVID-19 has had an impact on the 1,921 participants in this study. Now I'd like Dr. Swenor to talk with you about the global impact of COVID-19 on the lives of people with visual impairments. Bonnie.

**Bonnie:**

Thank you. As an epidemiologist with low vision, I've really paid careful attention to how the pandemic has unfolded through my perspective as a public health professional, my experience as a person with vision loss, and through data like what was just described. And I think it's really important to understand that the pandemic response has largely been data-driven. So what that means is that our policy and our public health strategies have primarily been based on COVID-19 surveillance information. That's the data that makes up those pandemic curves for the most part.

So as those curves and the COVID-19 estimates have shifted, so has our global response. That data-driven approach was taken on very early in the pandemic and was used in many locations to determine when to adopt things like social distancing, to close schools, to expand healthcare services. And it's also been really critical in helping to identify groups that are either at increased risk of COVID-19 and to determine groups that are most impacted by the changes that COVID-19 has brought about in our society.

And while that data driven approach really is standard protocol when responding to a public health crisis, we also have to consider that not all groups are always represented in that data.

**Text on screen:**

Live Q&A to follow…

**Bonnie:**

And the data for COVID-19 currently has a big gap. It's missing information from disability communities, from communities like ours, people living with vision loss. So while public health professionals really are working hard to track the virus, to identify high-risk groups, without information, without details like have just been described from certain parts of our community, people that have low vision or blind or really any other disability, this approach isn't reaching them.

So this survey, this Flatten Inaccessibility survey is an excellent tool to help to close that gap. What we're learning from this data, which has just been very well described, is that there are gaps, there are challenges, there are barriers to this response. This survey is giving us some evidence. It's giving a voice really to the community during this really challenging time.

And from that data and this time of a data-driven response to the pandemic, the survey can help us develop a roadmap to help policy makers, public health professionals, to improve the pandemic response for people like us, for people with vision loss. And so now I'm going to hand it back to Troy who's going to talk a little bit about how we can use this data to move forward.

**Troy:**

Thank you. Well, I'm going to close this out, I'm going to talk about the Flatten Inaccessibility Survey and working group roadmap and the future steps. So we believe there is value in repeating the survey this fall in 2020 and in spring of 2021 to see what the changes are. I mean this, this environment is fluid and changing and it will be useful to see how concerns and needs change over time.

**Text on screen:**

Live Q&A to follow…

**Try:**

And towards that end, resources, we need more resources or that this effort would benefit from more resources because there's just a lot of work and it's, and it's all volunteer, right, like this is, this is a community effort. And towards that end, you can either go to the website and use the "Contact Us" form, the Flatteninaccessibility.com website or directly contact Paul Schroeder - some of you may know Paul - and you can reach him at Paul@aira.io, A-I-R-A dot I-O.

And to wrap it up, we selected a quote from one of the participants: "We keep thinking we can outwit this thing and that things will ‘go back to normal’ Let's override normal and use this opportunity to make it better for us. Lemons to lemonade." I couldn't agree more. This is an opportunity to make permanent change, to improve access, and opportunity for this community.

So in closing, thank you so much for joining us all today. We look forward to hearing from you shortly in the Q&A. And please submit your questions using the Q&A feature. Thank you.

**On screen:**

Dr. Adams and Ms. Adams sit together in their living room:

**Text on screen:**

Kirk Adams, Ph.D., President & CEO, AFB

Roslyn Adams, Spouse & AFB Ambassador.

**Mrs. Adams:**

Hello again. Now as we move into the live portion of our Q&A, we’d like you to please be patient if we encounter any technical difficulties. And please enjoy the content.

**Part II: Live Q&A**

**On screen:**

Dr. Chanes-Mora, Mr. Otillio, Dr. Rosenblum, and Dr. Swenor appear remotely via a 4-way splitscreen. Then, Dr. Chanes-Mora.

**Paola:**

So thank you so much for joining us today and welcome to the Q&A section of this webinar. So it seems like we have gotten the first question come through and it is: **Do you know if communities are tapping food delivery systems like Meals On Wheels or other case management agencies?** I wonder, Penny, do you have any insight to this question?

**Penny:**

I don't have any direct insight. We did have a couple participants who talked about reaching out to delivery services through a church or through Meals On Wheels in their community. And we did have some participants who talked about that they had no way to get to the local food bank or food pantry in order to pick up a box. And that was a concern to them because they didn't have a way to get there. Again, another area where I think we need advocacy efforts in our field to ensure that if there are resources available, that people can access those resources if they have a visual impairment.

**Paola:**

Great, thank you, Penny. **And it seems like we have another question specifically about age distribution.** And I did say that a large proportion of our participants - I'll take that question - was of the older population. So I'm just going to report specific age ranges. So 7% were between the ages of 18 and 24, about 16% were between ages 25 and 34, 16% were also between 35 and 44, and 17% were about 45 and 54. So that does skew the remainder of our data in the older population. Another question that we just received is: **Do you have plans to determine solutions to the barriers such as maintaining a 6 feet distance from others?** Bonnie, do you have any insight for this question?

**Bonnie:**

Yeah, thank you. That's a really important next step. These data are certainly providing the barriers and the next step is to find the solutions. I don't personally have all the solutions to those barriers, but that is a really important one, is how do we engage in society during these times of restrictions of distancing?

**Troy:**

I can comment on that at least, Aira has a free five-minute call and I would say one of our most popular use cases, and it's growing, we can literally see people getting out and about more, is in some cases to help identify what the social distance is, where those lines are on the, you know, that they've been put out temporarily to indicate where you should stand. So, whether it's Be My Eyes or Aira, I think that is at least one tool. But more needs to be done.

**Paola:**

Thank you Troy and Bonnie for your answers. Next question that we have: **Do you have any guidelines on waiting for appointments without a car? Has this been discussed within the CDC?**

**Penny:**

I'll go ahead and say that again, in the qualitative data, this is a concern that's been shared, just going in for a regular doctor appointment or bloodwork and being asked to wait in your car until it’s your appointment, and not having a car. On a personal level, I've had one medical appointment and I had to stand outside for about 15 minutes in 90+ degree weather waiting because I didn't have a car to sit in to wait. We're still at the analyzing the data stage and I think one of the important things to share with the 300+ people who are on this call today is: you're part of the solutions for these challenges that have been identified by yourselves in your own personal experiences, but also that you're hearing through just this very small taste of the data we've gotten.

So advocating within your own community with healthcare providers, with legislatures, with companies to let them know this doesn't work for me because I have a visual impairment is important. In the coming weeks and months, I'm very confident that as the blindness field, we will continue to work to address some of these barriers through policy and through advocacy work. I know that's a focus for us here at the American Foundation for the Blind and for our consumer organizations especially, the American Council of the Blind, Blinded Veterans Association, and the National Federation of the Blind. But I do not know if the CDC has even put this on their radar quite frankly, and they should. Bonnie, do you have other thoughts?

**Bonnie:**

Yeah, thank you, Penny, I think that’s a wonderful response. I agree completely that the data is the start. Advocacy and making policy change and developing strategies like Troy indicated and bringing together diverse thought and diverse groups, like, I think this survey team represents to solve some of these challenges is really critical. And I agree, we can't stop with the data. It's just the beginning.

**Paola:**

We have two questions that are sort of interconnected. So Penny, I'll let you get the first half and I'll take the second half of that. The question is: **How were survey participants recruited?** And then I can speak a little bit about the second part of that question, which is: **Did you have any deafblind participants as well**? So if you could speak to how we recruited participants.

**Penny:**

Sure. There were 19 national organizations and companies and Troy did read over that list at the beginning of the presentation and it is also on the Flatteninaccessibility.com website. And each of those organizations made a commitment to reach out to their participant members, the customers that they serve. So there was blog posts, there was tweets there were direct emails that were sent. In addition, many of us posted on LinkedIn, Facebook, on our personal sites that the folks who were involved in the study. I know that some NFB presidents called constituents in their jurisdiction who weren't necessarily tech savvy as well.

So we did everything we could in that 10-day window when the survey was open to let as many people know about the survey as we could. Did we reach every visually impaired person in the United States? Absolutely not. Do we make a very strong effort on the behalf of bringing 16 entities together in a very short time? Absolutely. So we're proud of what we did, but no, we did not get everybody.

**Paola:**

Correct. We definitely tried really hard [laughter]. So, the second part of the question was specifically the deafblind community, was the second most common reported disability in the survey. We had almost 200 participants which equals to about all of the individuals that reported a second disability. It was about 22% of those secondly reported disabilities. So yes, we were able to have, I believe, a pretty good representation of this specific community.

The next question that we have is **regarding K-12 students specifically.** And I think this is probably a really great opportunity for us to be able to, to discuss what were the challenges that were found there. And then also this other survey that's still being analyzed specifically to K-12 students. So Penny, would you like to go through with that one?

**Penny:**

We had a small number of people who indicated that they themselves were were in charge of their child or grandchild’s education. We didn't ask how they were related to the child. And so, we haven't looked at that qualitative data to date yet for me to be able to really elaborate on that, but we, we will be. I do want to say, if you are interested in the impact of COVID-19 on the education of children who are visually impaired, including children with multiple disabilities and deafblindness, we also had a survey that ran from April 22nd to May 13th called Access and Engagement. And that survey specifically collected data from family members or guardians of children with visual impairments, and the teachers of students with visual impairments, and orientation and mobility instructors who are working with children with visual impairments, both in the United States and Canada.

We have 1,764 surveys we’re analyzing in parallel to Flatten Inaccessibility. So we're a busy crew, Paola and I. We have some other folks working with us on that Access and Engagement survey. So I don't have a lot to say right now about K-12 education because we just haven't analyzed the qualitative data. I don't-- Paola, is there a snippet you could give us from the quantitative that you have off the top of your head?

**Paola:**

As I reported, there definitely were concerns. We heard in some of the qualitative data as well concerns of parents not being able to teach their children because that material was not accessible to them. And that was definitely something that I, I remember very much so from going through some of them, the data. So more to come, be on the lookout for some more details about that. And Troy, we have this question. It looks like it may be the last question that we are able to take. Thank you so much. We received a plethora of questions. And we were only able to get through this many so thank you for your interest. It is: **How can we improve the accessibility of technology when it comes to accessing public transportation?** What are your thoughts about that?

**Troy:**

So I can give the Aira response. We've engaged a lot of public transit; we've done a pilot in Boston; we're working with New York; we've got an active pilot going in Houston. So as one provider of accessibility technology, ultimately it's about advocacy and the voice of the customer. So the more these transit authorities hear from their constituents that they need more accessible solutions, one of which being Aira, the easier it is to kind of deploy those solutions. So I think solutions like Aira, and there are many other solutions, really come from the fact that there's a demonstrated need and a demonstrated benefit, which, which would be my answer.

**Paola:**

Great. Well, thank you. That was the last question that we will be answering today. So thank you so much for participating. And I would like to remind everyone that the content of this webinar will be available at the AFB website in the near future. So thank you very much for joining us today.

**Part III: Sponsor & PSA**

**Narrator:**

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**Text on screen:**

AFB: American Foundation for the Blind (registered trademark).

**On screen:**

Visually impaired children and adults interact with their peers at school and at work.

**Narrator:**

The foundation we’re built on is creativity, independence, determination, and the pursuit of happiness. We are the American Foundation for the Blind: changing the way the world sees blindness. Together, with you, there is nothing we can’t do. To learn more, visit AFB.ORG.

**On screen:**

Expanding possibilities for people with vision loss.

**Narrator:**   
Again, Kirk and Roslyn Adams.

**Mrs. Adams:**

Thank you so much for joining us.

**Dr. Adams:**

And if you would like to help support our work creating a world of no limits for people who are blind, you can do so at AFB.org/Donate, and we would immensely appreciate it.

**Mrs. Adams:**

We truly would.

**Narrator:**

To find out more about this session and all of the Virtual Leadership Conference activities, go to AFB.org/VirtualAFBLC.

**Text on screen:**  
Session Presenters:  
Dr. L. Penny Rosenblum;  
Dr. Paola Chanes-Mora;  
Troy Otillio;

Dr. Bonnielin Swenor.

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Dr. Kirk Adams, Ph.D. – President and CEO, American Foundation for the Blind.  
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**EN****D**